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SOCIAL SECURITY DISABILITY REVIEWS: THE HUMAN COSTS

HEARING

BEFORE THE

SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE

NINETY-EIGHTH CONGRESS

SECOND SESSION

PART 1—CHICAGO, ILL.

FEBRUARY 16, 1984

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CONTENTS

Page

Opening statement by Senator John Heinz, chairman 1
Statement by Senator Charles H. Percy 2

CHRONOLOGICAL LIST OF WITNESSES

Heiser, Vera M., Darion, Ill 5
Vance, Donald, Chicago, Ill 7
Davy, Alberta L., Wheaton, Ill 18
Hudson, Mark C., Indianapolis, Ind., regional director, National Association of Disability Examiners 26
Naiditch, Zena, executive director, Developmental Disabilities Protection and Advocacy Board, Chicago, Ill 30
Samuels, Barbara, Chicago, Ill., Northwestern University Legal Clinic; accompanied by Joseph Antolin, Legal Assistance Foundation of Chicago, Ill 33
Snyder, Timothy H., director of programs, Access Living of Metropolitan Chicago, Ill 42
McDonald, Jess, Springfield, Ill., assistant to the Governor for human services 59
Granzeier, Robert W., Springfield, Ill., director, Department of Rehabilitation Services, State of Illinois 60
Bradley, Philip, Springfield, Ill., administrator, Bureau of Disability Adjudicative Services, State of Illinois 61

APPENDIX

Material related to hearing:

- Item 1. Background material on hearing 73
- Item 2. Memorandum related to evaluating social security disability claims; submitted by Joseph Antolin 80
- Item 3. Statement of Laura Guilfoyle, Illinois Alliance for the Mentally Ill, Evanston, Ill 115
- Item 4. Statement of Timothy Hagan, commissioner, Cuyahoga County, Ohio, on behalf of the National Association of Counties 116
- Item 5. Statement of Catherine Wilson, chapter service director, Chicago-Northern Illinois Chapter, National Multiple Sclerosis Association 117
- Item 6. Statement of Hortense Levkovitz, Wilmette, Ill 120
- Item 7. Statement of Michael Grice, Chicago, Ill 121
- Item 8. Statement of Christine LaVergne, paralegal advocate, Legal Advocacy Service, Guardianship and Advocacy Commission, Chicago, Ill 122
- Item 9. Statement of Bobbie Walker, Chicago, Ill 123
- Item 10. Statement of Martha A. McSteen, Acting Commissioner, Social Security Administration, Department of Health and Human Services 124

SOCIAL SECURITY DISABILITY REVIEWS: THE HUMAN COSTS

THURSDAY, FEBRUARY 16, 1984

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Chicago, Ill.

The committee met, pursuant to notice, at the Rehabilitation Institute of Chicago, Chicago, Ill., at 2 p.m., Hon. John Heinz (chairman) presiding.

Present: Senators Heinz and Percy.

Also present: John C. Rother, staff director and chief counsel; Isabelle Claxton, communications director; Paul Steitz, professional staff member; and Marcia Pape, legislative assistant to Senator Percy.

OPENING STATEMENT BY SENATOR JOHN HEINZ, CHAIRMAN

Chairman HEINZ. Good afternoon, ladies and gentlemen, and welcome to this hearing of the U.S. Senate Special Committee on Aging.

Before we begin I want to express thanks to Dr. Henry Betts and his absolutely outstanding staff for opening the doors of the Rehabilitation Institute of Chicago to the Special Committee on Aging. I think everybody here knows that Dr. Betts and this center are renowned, not just here in Chicago, but in rehabilitation circles across the country and around the world, and it is because of their innovative and truly expert treatment of the disabled.

This is no secret, that Dr. Betts and Senator Percy are very old and dear friends, indeed.

You know the reason that Senator Percy and I, both members of the Committee on Aging, are here is to examine an extraordinarily tragic issue, namely the continuing disability examinations and what they have done to a State, a city, and a group of local communities.

In Washington, we have heard a lot about national statistics and about the national crisis in the disability program. Today we are here to get a clearer picture of what is actually happening to people at the local level, how it affects local providers, how it affects institutions like this, how it affects this city, and the State of Illinois.

This is where the real problems have to be dealt with. In a real sense the Aging Committee is here because of Senator Percy. Senator Percy was the ranking member of this committee until his seniority on the Foreign Relations Committee forced him to make a choice. Had he not made that choice to go to the Foreign Relations Committee, which handles legislation, I would not be the chairman of this committee, and in every way Senator Percy remains, at the very least, our honorary chairman, and we are grateful to him for the work that he has done to make this committee such a valued instrument on behalf of our elderly and our disabled.

May I say just in passing that the committee is concerned that the Social Security Administration, the President, even the American people do not really know what they ought to know about the extent to which people are being hurt by these continuing reviews, and just how bad the situation really is.

We think the situation needs to be put in the light. We think people need to be aware of what is happening, and we believe that if we do that, comprehensive reform will be taking place shortly.

We are here in Chicago today because this is a critical time for the States, the courts, and the Congress. This week the Department of Health and Human Services is going to lift the national moratorium on reviews, and the States, including the Governor of Illinois, will be requested to start processing terminations again.

As a result, States are caught in a very difficult bind. On the one hand they want to protect their citizens from an inhumane and inflexible review process, and they also want to do what they are being told to do, or risk some kind of sanction or punishment.

So we are here today, in sum, because Congress has yet to act on resolving the crisis in the disability program. There is much good legislation pending in both the House and Senate, but that legislation will not become law unless the people want it to, and unless Congress recognizes that need.

Now, there is one other reason, and I speak somewhat personally about this, for us in Congress to act. As one American, I believe very deeply that this country happens to need Ronald Reagan's leadership, and I want to see the President reelected. And although these disability reviews were set in motion by the previous administration, the Carter administration, the failure to correct a flawed system that daily creates more disaster for genuinely disabled persons who paid for this insurance lends credibility to the President's opponents who talk about fairness.

The Democrats are going to make fairness the issue in the fall campaign, and I do not want to see my President hurt because of an insensitive bureaucracy that is running out of control.

When a few disabled people are rendered destitute and afraid, that is casework for a Member of Congress, or a Senator. When it is tens of thousands, it is time to bring the problem forcefully and urgently to the President's attention, and I believe these hearings will help to do exactly that.

As chairman of the committee, it is my great pleasure to turn to—if we allow the term—a gentleman I would only describe as my cochairman, the senior Senator from Illinois, my friend and yours, Chuck Percy.

STATEMENT BY SENATOR CHARLES H. PERCY

Senator Percy. Thank you very much, indeed, Mr. Chairman, and I accept the honorary title. I want to express my appreciation to not only the devotion you have had to this cause which the Senate Special Committee on Aging devotes itself to, but a subject I was thrust into at a very early age, 29, when I became chief executive officer of Bell & Howell. I found that I was automatically chairman of all the Bell & Howell employees who had retired, and those who would retire within the next 10 years. So I have been working many, many years in the problem of aging.

I think the hearings that you held and conducted on social security and the social security system brought to the country's attention the crisis that we faced in financing our social security system. The fact is that it was going bankrupt, and it had 36 million people worried as to whether they were going to get their checks.

Those committee hearings led to the Greenspan Commission report which was adopted by Congress. Social Security has now, for the next 75 years, been placed on a sound, solvent basis. No one must worry about whether or not they are going to get their checks.

So, too, I think these oversight hearings are extraordinarily important to examine the administrative situation in the social security disability program from a local perspective. Let us bring it right down to a great city, let us bring it right here to this institution, and see what effect it has.

I want to join you in expressing deep appreciation to Dr. Henry Betts, his fine staff, and the Rehabilitation Institute of Chicago for so graciously working with the Aging Committee—on such short notice—in hosting this important hearing. It is most appropriate we should hold a hearing on social security disability at some institute, and the Rehabilitation Institute of Chicago is one of the largest and best comprehensive rehabilitation centers in the Nation, if not the world. It was founded in 1951, and not only provides outstanding rehabilitation services to residents and patients, but serves as a center for research, education, and training.

Dr. Betts, the executive vice president and medical director of the institute, is a close, personal friend of mine, but may I correct the record? We are not old friends; Dr. Betts may be, but I am a young friend of Dr. Betts of long standing.

We have worked together in the construction of this building, in which Federal funds have been extraordinarily helpful. But truly the inspiration for what is being done here comes from Dr. Betts, from his outstanding staff, professional and administrative, and a truly dedicated board of directors. What help the Federal Government was able to provide would not have been at all feasible and practical without these fine people working with it.

I could not help but think back as again I saw Margaret Pfrommer, to the visit we had with Mrs. Sadat, the First Lady of Egypt, who just was absolutely thrilled. She herself is an expert in rehabilitation. Mrs. Sadat simply had never seen anything comparable to what we saw here.

The issue under consideration today, the social security disability program, is funded through payroll-tax deductions. It is a program that is fiscally sound, on its feet, has a surplus, and is a source of support for over 3.8 million mentally or physically disabled persons. In Illinois alone, there are over 140,000 recipients of disability benefits. For many of these persons, their disability check is their only source of income.

In March 1981, the Social Security Administration began reviewing the eligibility status of all beneficiaries on the disability rolls. I do not quarrel at all with an administrative agency occasionally reviewing, auditing, making absolutely certain that their program is going to the people for which it is intended, and that there is not abuse.

However, since March 1981, over 1.1 million disabled workers' cases have been reviewed, and in 45 percent of those cases benefits were terminated. This extremely high rate of termination, along with the fact that two-thirds of those who appealed to an administrative law judge had their benefits reinstated, led to a concern that the continuing disability reviews were being improperly administered. Obviously, it has led to a great deal of anguish.

I do want to add, to make the record complete, that there are 190,000 of those 1.1 million cases that have not been restored to the rolls. We might want to take a look at that 17.3 percent. Some of them were taken off for good and valid reasons, to keep the system sound. Our concern is about those who were taken off that never should have been taken off, and how much anguish has been caused to those who know that they are eligible to receive benefits, yet have been cut off.

Critics have charged that the continuing disability investigations were being conducted hastily and haphazardly, and that the reviews simply did not render accurate or valid conclusions about an individual's ability to work; 26 States, including our own State of Illinois, either are refusing to continue the review process or are under court order to use less stringent standards in carrying out the review.

The administration suspended further removals from the disability rolls in December, but that moratorium has now ended. The Illinois Department of Rehabilitation Services, along with agencies in the other States, now face instructions from the administration to resume processing disability cutoffs later this month.

Needless to say, all of this has generated a great deal of confusion and controversy.

Although the problems with the disability review process are quite complex, the controversy has centered on four key issues: (1) Whether an individual's medical condition has actually improved since the individual was put on the disability rolls; (2) the manner in which medical evidence is obtained and evaluated; (3) the great discrepancy in standards of evaluation between State disability examiners and administrative law judges; and (4) the degree to which the mentally disabled have been discriminated against by the continuing disability investigations. Clearly, Congress must take some action to overhaul the current disability review process.

Thank you.

Chairman Heinz. Senator Percy—I am sorry about this microphone. I gather it is not working too well.

Senator Percy. It is not Bell & Howell equipment.

Chairman Heinz. There is always room for improvement, that is correct.

We are very privileged to have three witnesses who have volunteered to tell us of their situation, their stories, their particular problems. Vera Heiser of Darien, Ill.; Donald Vance of Chicago; and Alberta Davy of Wheaton, Ill.

I am going to ask Vera Heiser if she would be our first witness.

STATEMENT OF VERA M. HEISER, DARION, ILL.

Ms. **Heiser**. Thank you.

Hello. My name is Vera Heiser. I am 43 years old. My medical history is this: I had rheumatic fever which was diagnosed in 1957 by our family doctor. He stated that my heart was so damaged that I had at the most 5 years to live.

I had my first open heart surgery on April 20, 1962. My mitral valve was replaced by a Starr-Edwars valve. My second open heart was performed on April 22, 1976. At that time the valve was replaced by a Hancock or pig valve. I remained on an aortic pump for 5 days after surgery, since my heart was not strong enough to work on its own.

My third open heart was on October 22, 1981, and the mitral valve was again replaced. I had been hospitalized 34 times since 1957.

Besides the open heart surgeries, I have had artery bypass surgery three times. The main artery in my right arm has been replaced and the arteries supplying my left and right leg have been bypassed. The last artery surgery was just done on November 29, 1983.

I have had seven cardiac catherizations. I have gallstones. I suffer from severe and debilitating migraine headaches. I have a duodenal ulcer. I am allergic to most drugs. I have food allergies, blood and blood products allergies. I have had at least five TIS's, transient ischemic attacks. They are ministrokes. The most recent one was in April 1983. These blood clots have caused memory loss and impaired movements in my arms, legs, and face.

I have been in fibrillation since 1980, and this is really aggravated by stress. I suffer from depression. I had an emergency hysterectomy at 29 because I hemorrhaged. I hemorrhaged again in July 1983 after an arteriorgram, and again in December 1983 after my last vascular surgery. I required blood transfusions, and had severe allergic reactions to them. I have arthritis in my joints and spine.

On December 10, 1981, shortly after I came home from the hospital after my third open heart surgery, I received a letter from Social Security stating that my claim to disability was being investigated. I called the adjudicator in Springfield, and he told me to write a letter stating my condition, and then forget about any investigation.

Then in April 1982, I again received a letter, from a different adjudicator, stating that I was being investigated. I was told to submit letters from my doctors, which I did.

On September 2, 1982, after many phone calls and letters, I received the notice that my disability benefits had ended and I had 10 days to submit additional evidence if I wished a review.

A new adjudicator was assigned, and my doctors were asked to submit more extensive information. My doctors responded promptly. I was also sent for a psychiatric evaluation and to a rehabilitation counselor. The psychiatrist told me he was sure I would be reinstated.

I have a letter from the rehab counselor, and he also states that he feels I am totally disabled. A letter was written by my pastor. Again a denial came and my benefits were stopped. I was not considered disabled after September 1982, according to this letter.

I need the medicare as well as my monthly disability check. We literally went through hell. We had to borrow money. My prescriptions are expensive. I did not go to see my doctor for a while because I was afraid to make an additional bill.

We did file for a hearing through my attorney and I was officially reinstated on May 31, 1983.

To tell you of the agony, anger, fears, frustration, tears, and the wish that I could end my life, could take forever. I have been made to feel that I was taking something that I did not deserve.

Despite my open heart surgery in 1962, when I was 21 years of age, I went back to work. I like to work, and I love my independence. I worked even though I had two vascular surgeries and was hospitalized for 3 months for the birth of my daughter. I worked until I was hospitalized with a stroke in 1969.

Since I was forced to quit work and apply for social security benefits, I have been made to feel like a second-class citizen, that I am a goof-off, and unworthy. It is frustrating and humiliating.

I would rather work than exist the way I do. I have no social life. My life goes from one hospitalization to the next, one doctor's visit to the next, one pill to the next, and from one migraine to another. I am in constant fibrillation which increases in rate and severity when I am upset and I often blackout.

From April 1982 to this day I am easily upset and afraid. I feel frustrated and disgusted. I am afraid to go to the mail box because I do not know what I might find. Whenever there is a letter from social security, I am afraid to open it.

My hands shake, my face flushes, my fibrillation rate increases and my breathing is labored.

Even though I was told that I would not be reinvestigated for 2½ years, I really do not believe it. I thought it was beyond the question of a doubt that I am totally and permanently disabled; yet I have gone through this unbelievable time.

I live with fear 24 hours a day. It has put a strain on me, as wife, a mother, and a friend. This and the fact that I am so limited in my physical capabilities gives me much time to think. This has been a nightmare for me. I am always near tears. I often feel that if I ended my life this nightmare might end. Why must the disabled be made to feel so unworthy of these benefits?

Anyone who thinks this is easy, let me tell them I would gladly change places.

I do not have all the solutions to the problems with social security disability benefits, but I would suggest ways must be found to be less degrading to any recipient of social security. I pray that none of you ever have to accept the "charity" of social security. It is degrading, demoralizing, and humiliating. I will end with saying that.

Thank you.

Chairman HEINZ. Ms. Heiser, thank you.

What you have said, before I call Mr. Vance, requires, I think, two things to be said, not just to you, but to everybody else.

First of all, the social security disability insurance system is an insurance policy against being totally and permanently disabled, as you have been, that you have bought and paid for and earned. When you were working, you worked the required number of quarters under social security, and the payroll tax that went into social security was divided in three pieces. Part went into old age and survivors fund, and part went into the disability insurance fund, and part went into the health insurance, the medicare fund.

You were cut off in September 1982 from two of the three benefits, your disability payments and the medicare you needed to pay for the 34 times you were hospitalized. You were cut off from a program which you had contributed to with the certain knowledge and full faith that when you needed that program, it would be available to you.

You have pointed out the way you have been humiliated by the system, and made to feel that it was not a program you had a right to be a part of, even though you paid every day you were working to be a part of it.

The other comment I would make is that the disability insurance program, that trust fund which is separately funded by a particular specified tax rate, has never, is not now and will not be in financial jeopardy. It is in such good shape that by the year 1996 the revenues going into the disability fund will be twice the outlays going out of it. The trust fund will have a huge surplus of almost $50 billion at that point.

So there is neither fiscal rhyme nor fairness reason to the way you have been treated, and I wanted you to know that, because nobody deserves to be treated the way you have just described.

Mr. Vance?

Senator Percy and I will have questions for you, but I just wanted to make that clear to everybody, that was all.

Mr. Vance?

STATEMENT OF DONALD VANCE, CHICAGO, ILL.

Mr. **Vance**. My name is Donald Vance. I am 53 years old. I was born on December 9, 1930, with spina bifida and club feet. Spina bifida is a birth defect that is caused by the neural tube in the spine not closing and leaving those nerves and spinal fluids open to damage.

In 1930, the odds of surviving with spina bifida for more than 1 year were less than 10 percent. Now with better surgical procedures and better shunts for hydrocephalus, a common complication with spina bifida, the chances for a child to live a long and meaningful life have just about reversed themselves.

Shortly after I was born I was operated on to close the opening on my spine. I was not supposed to be able to walk, according to the doctors, but by the time I was 3, I could walk with a very bad limp. By this time it was also discovered that I was incontinent in bladder and bowels, and that I had no nerves working in my buttocks, and I had diminished feelings in my legs.

At the age of 13, I went into the University of Michigan Hospital for a series of operations to correct my club feet. They were able to straighten out my feet to the point where I was no longer walking on the sides of my feet, but I still limped.

In 1974, my nerves in my legs and midsection had deteriorated to the point that I had lost all feelings in my stomach, sex organs, and upper thighs. I went into Evanston Hospital for spinal surgery. Dr. Ciric, neuorsurgeon, removed some of the scar tissue from the original operation. This did not give me back any of the feelings I had lost, but it did keep it from getting any worse at that time. My wife and the doctors advised me to try to get a disability pension at that time, but I decided that I would rather go back to work, which I did after 6 months.

In July 1978, I was working as a shuttle-bus driver for a highrise on the northside of Chicago. I had a migraine attack while I was on the Outer Drive, and managed to pull the bus to the side of the road and had a cab driver call an ambulance for me. They took me to Ravenswood Hospital emergency room and admitted me for tests. One of the tests showed that the left ventricle in my brain had dilated, which meant that I had hydrocephalus.

I lost my job because I was sill having migraine attacks at this time. I tried to find another job, but because of my physical condition and age I could not.

I then filed for help with social security and welfare. I started to receive help from welfare, and then I received social security checks.

In 1979, I went into Evanston Hospital for tests because I was now losing the feelings in the last two fingers of my left hand. They discovered that I had a pinched nerve in my neck from arthritis. They also ran more CAT scans on my head for progress on the hydrocephalus.

Early in 1980, I had surgery for a cyst on my buttock. Then in September 1980, my hydrocephalus had gotten to the point where they had to put a shunt in my head to drain the fluid from my brain.

On February 25, 1983, I got a notice from Social Security that they were going to review my eligibility for the benefits. In March, they sent me to the DORS clinic for a physical exam. On April 20, I received a notice that my benefits were going to be stopped. I went back to Social Security and filed an appeal for reconsideration.

In June, I went back into Evanston Hospital for another cyst removal on my right buttock.

On July 27, 1983, I received a notice from Social Security that my appeal had been denied. I then filed for a judicial hearing.

On September 28, 1983, I reentered Evanston Hospital for a cyst removal, again on my right buttock. They removed the cyst and found at that time that I had an infection, osteomyelitis, in the bone in my right buttock. I was put on antibiotics for 8 weeks. They also took me back to surgery to remove more of the infected bone, and took a flap of skin and flesh from my right thigh and moved it back to the buttock. This transplant or graft did not take, so they again took me back to surgery and removed the flesh and sewed me up.

I left the hospital on the 2d of December with a warning from the doctor not to sit on my buttock for more than 2 hours at one time. With the arthritis I have in my ankles, knees and hips, this additional problem limits my mobility and usefulness to less than half of what it was before I applied for social security.

While I was in the hospital, I received word that my hearing was scheduled for November 22, 1983. I got in touch with the Legal Assistance Foundation of Cook County. They put me in touch with Juanita Penuala, a paralegal. She filed for a postponement, which they granted. I had my hearing a few weeks ago. I am still waiting for Judge Stillerman to notify me of his decision.

Now, when I went to school as a child, I was taught in civics class that according to our system in this country, a person is considered innocent until proven guilty, and that the courts have to prove that he is guilty. In this case the opposite is true. Now we have to prove that we have not gotten better, instead of Social Security proving that we have.

As far as the review boards go, I realize that they are composed of doctors and other experts, but I wonder if they have a neurologist on the board who has any real experience with treating spina bifida. I do not think so, or they would know that at my age spina bifida and the related troubles do not get better—instead they get worse. And if they can be wrong about my disability, how many other types of disabilities have they been wrong about?

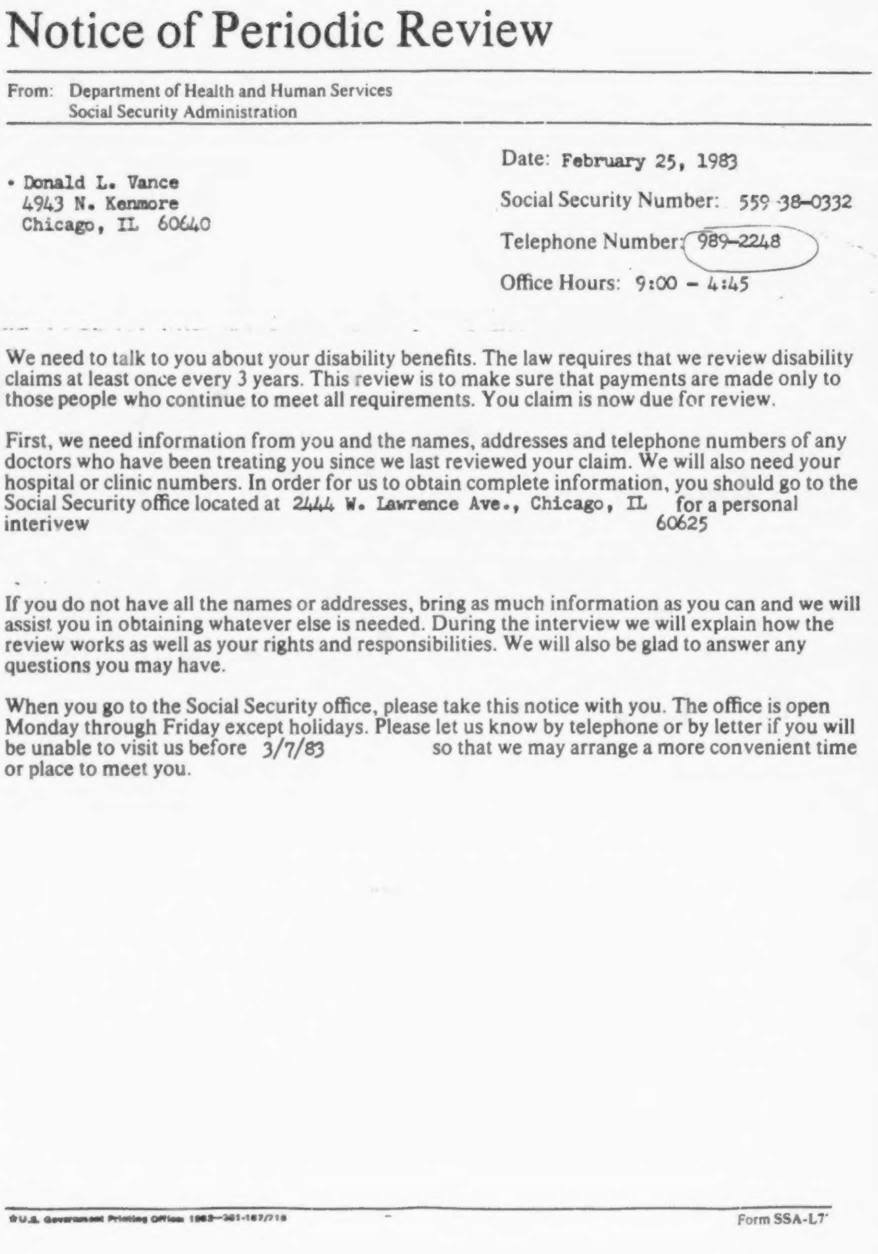
One of the ironies of this that we have President Reagan on the one hand telling us that we have to do everything in our power to make sure that children born with handicaps are given every chance to live. I agree wholeheartedly with this. Then on the other hand, when these same people get older and need help, they do not want to help us. I know that the social security system needs to be reorganized and changed, but let us not go at it with an axe, when a scalpel will do. Let us be a lot more humane and selective about who will get cut off.

In conclusion, let me say that in my case, if I am cut off, I will have to go to State welfare to stay alive, and anybody who has ever been on welfare will tell you that this is not really living, it is slow starvation. It is not even enough money to pay your rent, let alone such luxuries as clothes, prescriptions, food, and a little pocket money.

Thank you for allowing me to make this presentation. I hope that my case has helped you to understand the urgency and the scope of this problem,

Chairman HEINZ. Mr. Vance, thank you very much.

[Material related to Mr. Vance follows:]



Notice of Periodic Review

From: Department of Health and Human Services
Social Security Administration

Date: February 25, 1983

Social Security Number: 559-38-0332

Telephone Number: 989-2248

Office Hours: 9:00 - 4:45

• Donald L. Vance
4943 N. Kenmore
Chicago, IL 60640

We need to talk to you about your disability benefits. The law requires that we review disability claims at least once every 3 years. This review is to make sure that payments are made only to those people who continue to meet all requirements. You claim is now due for review.

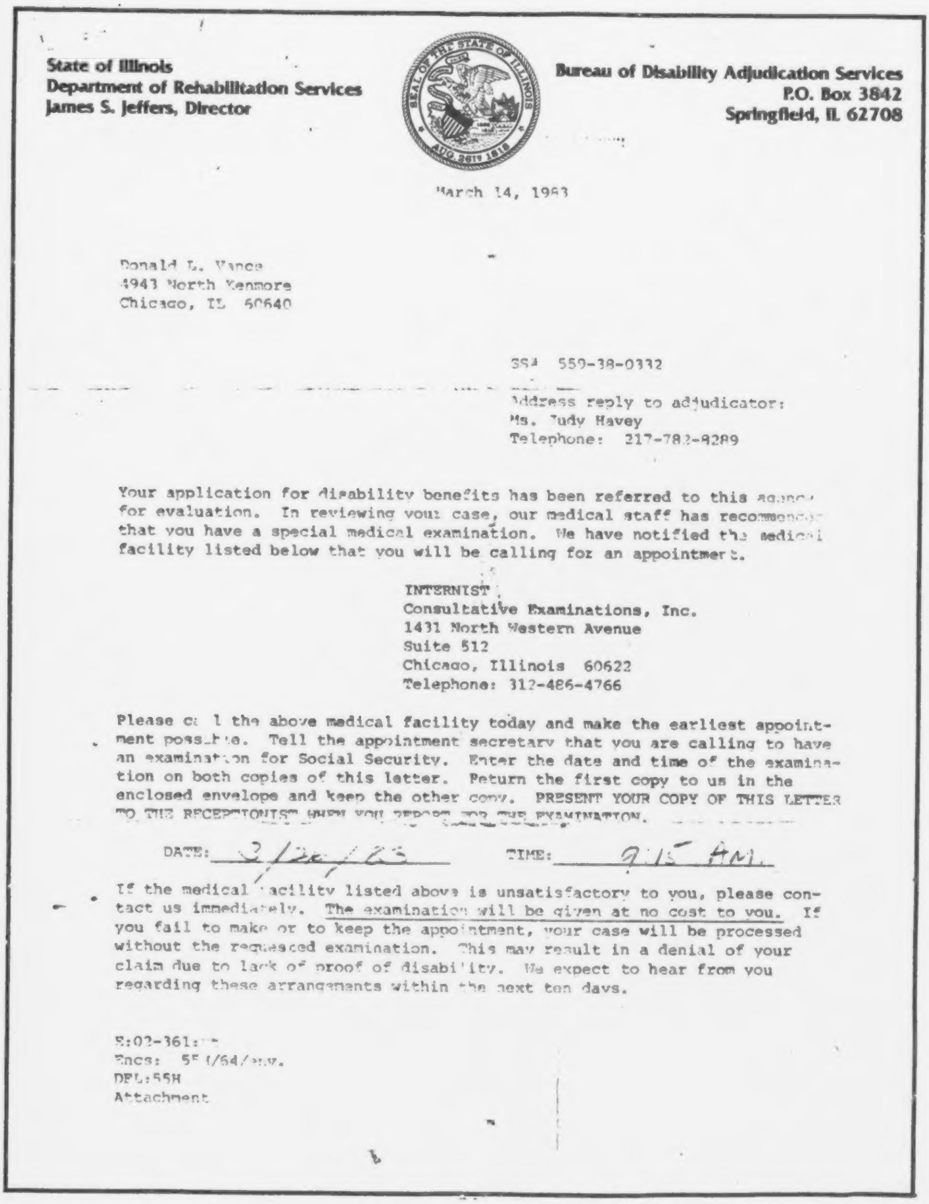
First, we need information from you and the names, addresses and telephone numbers of any doctors who have been treating you since we last reviewed your claim. We will also need your hospital or clinic numbers. In order for us to obtain complete information, you should go to the Social Security office located at 2444 W. Lawrence Ave., Chicago, IL 60625 for a personal interivew

If you do not have all the names or addresses, bring as much information as you can and we will assist you in obtaining whatever else is needed. During the interview we will explain how the review works as well as your rights and responsibilities. We will also be glad to answer any questions you may have.

When you go to the Social Security office, please take this notice with you. The office is open Monday through Friday except holidays. Please let us know by telephone or by letter if you will be unable to visit us before 3/7/83 so that we may arrange a more convenient time or place to meet you.

☆U.S. Government Printing Office: 1982—381-187/718

Form SSA-L7



State of Illinois
Department of Rehabilitation Services
James S. Jeffers, Director

AUG. 26TH 1818

Bureau of Disability Adjudication Services
P.O. Box 3842
Springfield, IL 62708

March 14, 1983

Donald L. Vance
4943 North Kenmore
Chicago, IL 60640

SSA 559-38-0332

Address reply to adjudicator:
Ms. Judy Havey
Telephone: 217-782-8289

Your application for disability benefits has been referred to this agency for evaluation. In reviewing your case, our medical staff has recommended that you have a special medical examination. We have notified the medical facility listed below that you will be calling for an appointment.

INTERNIST
Consultative Examinations, Inc.
1431 North Western Avenue
Suite 512
Chicago, Illinois 60622
Telephone: 312-486-4766

Please call the above medical facility today and make the earliest appointment possible. Tell the appointment secretary that you are calling to have an examination for Social Security. Enter the date and time of the examination on both copies of this letter. Return the first copy to us in the enclosed envelope and keep the other copy. PRESENT YOUR COPY OF THIS LETTER TO THE RECEPTIONIST WHEN YOU REPORT FOR THE EXAMINATION.

DATE: 3/24/83 TIME: 9:15 AM.

If the medical facility listed above is unsatisfactory to you, please contact us immediately. The examination will be given at no cost to you. If you fail to make or to keep the appointment, your case will be processed without the requested examination. This may result in a denial of your claim due to lack of proof of disability. We expect to hear from you regarding these arrangements within the next ten days.

E:02-361:
Encs: 5F/64/env.
DFL:55H
Attachment

Social Security Notice

DT

From: Department of Health and Human Services
Social Security Administration

Donald L. Vance
4943 N. Kenmore
Chicago, IL 60640

Date: APR 20 1983

Claim Number: 559-38-0332

This notice concerns your continuing entitlement to benefits under the Social Security Disability Program.

The law provides that an individual's disability period shall end if the person is able to do substantial gainful work. The law also provides that an individual will receive benefit payments for the month disability ends and the following two months. The medical evidence in your case shows that you became able to do substantial gainful work in 04/83. Accordingly, the last disability benefit to which you are entitled is for the month of 06/83.

The following reports were used to decide your claim. We did not obtain any other reports because the ones shown below had enough information to evaluate your condition:

Parkview Hospital, outpatient treatment from 12/82 through 01/83; J. Graner, M.D., consultative Internist examination report of 03/31/83; N. Vick, M.D., report of 03/14/83.

You said that your disability continues because of congenital spina bifida, club feet, ulcers on the buttocks, hydrocephalus and arthritis of the knees and feet. The evidence in file shows that though you may have discomfort, you are able to move about and use your arms, hands and legs in a satisfactory manner. The evidence shows your condition has not resulted in severe weakness, paralysis, or loss of control of your limbs. Special breathing studies show that your breathing capacity is satisfactory. Special testing of your heart before and after exercise shows that your heartbeat and function are satisfactory. No other severe problems are noted. Based on the medical evidence, you can do light work, for example, lift a maximum of 20 pounds and sit or stand and walk through a six to eight hour day. According to your description of the job of Bus Driver that you performed in the past for approximately one year, we have determined that you can return to this job. Therefore, we have determined that your disability has ceased.

The decision on your claim was made by the Social Security Administration (not your personal physician) on the basis of a disability determination by an agency of the State in which you live. Physicians and other trained disability evaluation personnel in the State agency participated in making this determination.

DEPARTMENT OF HEALTH AND HUMAN SERVICES
SOCIAL SECURITY ADMINISTRATION

TOE 710

Form Approved
OMB No. 72-R0552

REQUEST FOR RECONSIDERATION

The information on this form is authorized by law (20 CFR 404.910 – 404.914). While your responses to these questions is voluntary, the Social Security Administration cannot reconsider the decision on this claim unless the information is furnished.

(Do not write in this space)
4/99
4/27/83

NAME OF CLAIMANT: Donald L. Vance

NAME OF WAGE EARNER OR SELF-EMPLOYED PERSON (If different from claimant.):

SOCIAL SECURITY CLAIM NUMBER: 359-38-0332

SUPPLEMENTAL SECURITY INCOME CLAIM NUMBER:

SPOUSE'S NAME AND SOCIAL SECURITY NUMBER (Complete ONLY in Supplemental Security Income Case):

CLAIM FOR (Specify type, e.g., retirement, disability, hospital insurance, supplemental security income, etc.): Disability Cessation

I do not agree with the determination made on the above claim and request reconsideration. My reasons are:

Due to my migraines & hydrocephalus I cannot get a license to drive. I cannot sit stand or walk through a six to eight hour day, especially due to the incontinence.

NOTE: If the notice of the determination on your claim is dated more than 65 days ago, include your reason for not making this request earlier. Include the date on which you received the notice of the determination.

I am submitting the following additional evidence (If none, write "None,"):

None

Signature (First name, middle initial, last name) (Write in ink)
SIGN HERE ➧ Donald L. Vance

Date (Month, day, year): 4/27/83

Telephone Number: 663-1562 leave message

Mailing Address (Number and street, Apt. No., P.O. Box, or Rural Route): 4943 N. Kenmore

City and State: Chgo Il

ZIP Code: 60640

Enter Name of County (if any) in which you now live: Cook

Witnesses are required ONLY if this request has been signed by mark (X) above. If signed by mark (X), two witnesses to the signing who know the person requesting reconsideration must sign below, giving their full addresses.

1. Signature of Witness

Address (Number and street, City, State, ZIP Code)

2. Signature of Witness

Address (Number and street, City, State, ZIP Code)

FOR SOCIAL SECURITY OFFICE USE ONLY

SOCIAL SECURITY OFFICE ADDRESS

2444 W. Lawrence Ave.
Chicago, Ill. 60625

Form SSA-561-U2 (4-80) (Formerly SSA-561)
Prior editions may be used until supply is exhausted

CLAIMANT'S COPY

Social Security Notice

dt

From: **Department of Health and Human Services**
Social Security Administration

Date: JUL 27 1983
Claim Number: 559-38-0332

Donald L. Vance
4943 N. Kenmore
Chicago, Illinois 60640

In view of your request for reconsideration, all the information about your claim has been carefully evaluated. It has been determined that the previous decision was proper under the law.

A period of disability was established for you beginning 07-09-78. The law provides that an individual's disability period shall end if the person is able to do his or her usual occupation or any kind of substantial gainful work considering the person's age, education and work experience. The law also provides that an individual will receive benefit payments for the month disability ends and the following 2 months. The evidence in your case shows that you became able to do substantial gainful work in 04-83. Therefore, it has been determined that entitlement to disability benefits ended with the month of 06-83.

On reconsideration, all the evidence was reviewed, and no condition was disclosed that would prevent you from working. Below is an explanation of the decision we made on your claim and how we arrived at it.

In reviewing your file, the following reports were used to decide your claim.

Nicholas Vick, M.D., report dated 05-28-83; Charles Drueck, III, M.D., report of 06-13-83; Parkview Hospital, outpatient treatment from 12-82 through 01-83; J. Graner, M.D., consultative examination report of 03-31-83; N. Jack, M.D., report of 03-14-83.

You said that your disability continues because of congenital spina bifida, clubbed feet, ulceration on buttocks, hydrocephalus, arthritis of knees and feet, and you cannot stand and walk through a 6 to 8 hour day especially due to incontinence. The medical evidence does show that you have congenital spina bifida, hydrocephalus, and ulceration on your buttocks. There is no indication of a severe problem because of clubbed feet or arthritis of the knees. Evidence shows you are able to stand and walk without the use of cane or crutches and you are able to bend and flex your joints to perform normal functions to some degree. Based on the medical evidence, you can do light work, for example, lift up to 20 pounds and sit or stand and walk through a 6 to 8 hour day. According to your description of the job of shuttle bus driver that you performed in the past for over 1 year, we have concluded that you can return to this job. Therefore, we have determined that your disability has ceased.

This determination was made by an Agency of the State and not by the individuals or agencies that submitted reports.

DEPARTMENT OF HEALTH AND HUMAN SERVICES
SOCIAL SECURITY ADMINISTRATION
OFFICE OF HEARINGS AND APPEALS

Form Approved
OMB No. 0960-0269

SEE PRIVACY ACT NOTICE ON REVERSE SIDE OF FORM.

REQUEST FOR HEARING

Take or mail original and all copies to your local Social Security office.

CLAIMANT
Donald Vance

WAGE EARNER *(Leave blank if same as above)*

SOCIAL SECURITY NUMBER
559-38-0332

SPOUSE'S NAME AND SOCIAL SECURITY NUMBER
(Complete ONLY in Supplemental Security Income Case)

(Check One) Initial Entitlement ☐ Termination or other Post-Entitlement Action ☒

Type Claim (Check ONE)

Retirement or Survivors . . . . Only ☐ (RSI)
Disability, Worker or Child . . . . Only ☒ (DIWC)
Disability, Widow or Widower . . . . Only ☐ (DIWW)

SSI, Aged . . . . Only ☐ (SSIA) | SSI, Aged . . . . With Title II Claim ☐ (SSAC)
SSI, Blind . . . . Only ☐ (SSIB) | SSI, Blind . . . . With Title II Claim ☐ (SSBC)
SSI, Disability . . Only ☐ (SSID) | SSI, Disability . . With Title II Claim ☐ (SSDC)

Other (Specify)

I disagree with the determination made on the above claim and request a hearing. My reasons for disagreement are:

I am too disabled to work due to the combination of my migraine headaches, the spina bifida and other previously mentioned ailments.

Check one of the following:

☐ I have additional evidence to submit (Attach such evidence to this form or forward to the Social Security Office within 10 days.)

☒ I have no additional evidence to submit.

Check ONLY ONE of the statements below:

☒ I wish to appear in person

☐ I do not wish to appear at a hearing. I request that a decision be made on the basis of the evidence in my case.

Signed by: (Either the claimant or representative should sign. Enter addresses for both. If claimant has a representative, Form SSA-1696-U3 (Appointment of Representative) must be completed.)

SIGNATURE OR NAME OF CLAIMANT'S REPRESENTATIVE
☐ ATTORNEY ☐ NON ATTORNEY

ADDRESS

CITY, STATE, AND ZIP CODE

TELEPHONE NUMBER

CLAIMANT'S SIGNATURE
Donald L. Vance

ADDRESS
4937 N Kenmore

CITY, STATE, AND ZIP CODE
Chicago Il 60640

DATE: 8-2-83

TELEPHONE NUMBER
(312) 878 5623

(Claimant should not fill in below this line)

TO BE COMPLETED BY SOCIAL SECURITY ADMINISTRATION

Is this request timely filed? ☒ YES ☐ NO
If "No" is checked: (1) Attach claimant's explanation for delay, (2) Attach any pertinent letter, material, or information in the Social Security Office.

Interpreter Needed None
(Language, including sign language)

ACKNOWLEDGMENT OF REQUEST FOR HEARING

This request for hearing was filed on 8 2 83 at 2444 W. Lawrence

The Administrative Law Judge will notify you of the time and place of the hearing at least 10 days in advance of the hearing.

For the Social Security Administration:
By: Peter J Pagano
(Signature)
CR
(Title)
2444 W Lawrence
(Street Address)
Chicago Il 60625
(City, State, and Zip Code)
Servicing Social Security Office Code 449

Form HA-501-US (12-81)
DESTROY PRIOR EDITIONS

CLAIMANT

DEPARTMENT OF
HEALTH AND HUMAN SERVICES
SOCIAL SECURITY ADMINISTRATION

APPOINTMENT OF REPRESENTATIVE

I appoint JUANITA PENUELA
(Print or Type Name and Address of Representative)

to act as my representative in connection with my claim under Titles II, XVI or XVIII of the Social Security Act and/or Title IV of the Federal Coal Mine Health and Safety Act based on the social security record of

NAME	SOCIAL SECURITY NUMBER
DONALD VANCE	559-38-0332

I authorize my representative to make or give any request or notice; present or elicit evidence; obtain information; and receive any notice in connection with my claim wholly in my stead.

Date 12/12/83

Signature Donald Vance
(Claimant)

Address 4937 N. KENMORE

ACCEPTANCE OF APPOINTMENT

I, JUANITA PENUELA, hereby accept the above appointment. I certify that I have not been suspended or prohibited from practice before the Social Security Administration; that I am not, as an officer or employee of the United States, disqualified from acting as the claimant's representative; and that I will not charge or receive a fee for the representation unless it has been authorized in accordance with the laws and regulations referred to on the reverse side hereof. In the event that I decide not to charge or collect a fee for the representation I will notify the Social Security Administration.

I am a Paralegal Legal Assistance Foundation
(Attorney, union representative, relative, law student, etc.)

Date Dec 12, 1983

Signature Juanita Penuela
(Representative)

Address 4753 N Broadway #1118
Chicago, Il. 60640

(See Important Information on Reverse)

FORM SSA-1696-U3 (8-77) (FORMERLY SSA-1696)
PRIOR EDITIONS MAY BE USED UNTIL SUPPLY IS EXHAUSTED

CLAIMANT'S COPY

DEPARTMENT OF HEALTH AND HUMAN SERVICES
SOCIAL SECURITY ADMINISTRATION
OFFICE OF HEARINGS AND APPEALS

NOTICE OF HEARING

(Claimant–Wage Earner) VANCE, Donald

Claim for Continuance of Disability Insurance Benefits (Title II)

TO:

☒ Cessation Case
☐ Closed Period Case

559-38-0332
(Social Security Number)

Donald Vance
4937 N. Kenmore
Chicago, Illinois 60640

IN ORDER TO PROVIDE YOU WITH AN OPPORTUNITY TO FULLY PRESENT YOUR CASE, THE DATE AND TIME OF THIS HEARING HAVE BEEN SET ASIDE ESPECIALLY FOR YOU. YOUR FAILURE TO APPEAR WITHOUT GOOD REASON WILL CAUSE DISMISSAL OF YOUR REQUEST FOR HEARING.

Pursuant to your written request, a hearing will be held by the undersigned, an Administrative Law Judge of the Office of Hearings and Appeals. YOU ARE HEREBY NOTIFIED TO APPEAR ON

Tuesday (Day of Week), November 22, 1983 (Full Date) at 8:30 o'clock in Room 1000

(Building), 500 Davis (Number and Street), Evanston (City), Ill (State)

ISSUES: The general issues to be decided are whether you continue to be entitled to a period of disability under section 216(I) of the Social Security Act, and to disability insurance benefits under section 223(a). The specific issue to be decided is whether your impairment or impairments are of sufficient severity to prevent you from engaging in substantial gainful activity, considering your age, education, and work experience. If it is found that you are able to engage in substantial gainful activity, an additional issue to be decided is the month disability ceased.

REMARKS: You may bring your physician to the hearing to testify on your behalf.

Also, please bring with you to the hearing the medications you are presently taking. If you wish to review your ;file, please arrive at least 15 minutes early.

IMPORTANT – Please sign and return at once the enclosed acknowledgment form notifying me whether you will be present at the scheduled hearing. No postage is required on this form. If an emergency arises preventing your appearance after you mail the acknowledgment form stating that you will be present, notify me promptly and give your reasons. Also, indicate how soon you will be able to attend a hearing.

READ THE OTHER SIDE OF THIS NOTICE FOR FURTHER INFORMATION REGARDING YOUR HEARING

Enclosure

Administrative Law Judge
(Signature):
(Type name in full): Irving Stillerman

Date: 10-21-83

Telephone Number: 312-869-5684

Hearing Office Mailing Address:
Office of Hearings and Appeals, SSA
500 Davis, Room 1000
Evanston, Illinois 60201

cc: Representative (Name and Address)

cc: Social Security Office (Street Address)
2444 W. Lawrence
Chicago, Ill

Form HA-5075-U5 (8-81) Use prior editions

CLAIMANT

Chairman HEINZ. Ms. Davy?

STATEMENT OF ALBERTA L. DAVY, WHEATON, ILL.

Ms. DAVY. Hello. My name is Alberta Davy. I first received disability benefits in 1976. The reason I am no longer able to work is that I have a severe case of multiple sclerosis.

I was first diagnosed as having multiple sclerosis in 1966. Despite my condition, I continued to work for another 10 years as a keypunch operator. However, little by little I got worse. It has been a long, slow process.

First I just cut down my work to part time. Eventually the fatigue, pain, and bad vision forced me to quit working altogether. My fingers became so weak I could not work the machine any longer. My vision became so bad I could not keep track of the lines.

Finally, in 1976, I applied for disability benefits. My application was accepted, and I began receiving monthly payments that gave me a basic income to live on.

I desperately wish I could work. I do not enjoy being inactive. Every year I pray and hope some new medicine or therapy will help me overcome the limitations of my condition and allow me to go back to work.

I have tried everything to improve my condition and reduce the pain and fatigue. I went all the way to California to have vertebral artery surgery, both right and left. That is not medically approved. I have had ACTH drug therapy. I had a dorsal column stimulation implant to relieve pain. Nothing has worked.

Presently I can walk a total of about a block on good days. I have about one-half—about one-quarter the energy of most people. Yet with me, like with all people with multiple sclerosis, my condition is invisible. You cannot see the pain. I do not broadcast my fatigue, but in reality I can be active only during a very small part of any day, any week, or any month.

Despite the fact my condition has continually worsened, social security nonetheless determined I was no longer eligible for benefits in May 1983. They sent me to one of their doctors last April. That doctor knew nothing about multiple sclerosis. That doctor said I have fine finger motion. That is ridiculous. I can barely use my fingers. That doctor said I can move around unassisted. But she did not say anything about the fact that I cannot walk more than 200 yards.

After the doctor's examination I was notified that my benefits would cease. Naturally I appealed that decision, and eventually social security overturned its decision after another doctor looked at me, and my benefits were given back.

Overall, I feel very fortunate that my benefits were ultimately reinstated. I know many people have not had this good fortune, to be given their eligibility back.

Though I have been lucky, I still feel as though I, or anybody else, should not have had to go through such a stressful, tension-filled process. People with multiple sclerosis do not need extra anxiety. We have enough as it is.

Further, no American citizen should have to be put through a demeaning, degrading and unfair review process. This simply has to stop. I hope Congress can solve this problem soon. This is not the kind of treatment we deserve.

I do have just a little bit here I would like to read to you from our MS magazine.

Chairman **Heinz**. Please proceed, Ms. Davy.

Ms. **Davy**. Dr. Floyd Davis, director of the MS Center at Rush-Presbyterian-St. Luke's Medical Center in Chicago says fatigue is a universal complaint and a special phenomenon in patients with multiple sclerosis. You don't have to work up a sweat to be fatigued—sometimes after just a short period of walking or writing or reading, a person has to just stop functioning for a while, he says.

And then the doctor goes on to tell why demyelinated nerve fibers appear to use much more energy conducting nerve impulses than normal fibers, and as a result they fatigue with use, causing increased weakness and uncoordination.

Weakened muscles put an extra workload on stronger muscles, causing them to fatigue more rapidly.

Depression and frustration at having a chronic disease such as MS—and the two people that have just spoken—can result in fatigue.

MS persons also experience normal muscle fatigue like anyone else, but because of all the energy sapped by their disease, this normal fatigue is more common and occurs more quickly.

Dr. Davis clarifies fatigue in persons with MS even further, by maintaining that fatigue can either be based on the muscles of the central nervous system, and it doesn't take much to fatigue the central nervous system.

Not only do people with MS look well, they feel well until they begin a certain activity. They function beautifully for a while, and then all at once they have to stop, because the nerve impulses just aren't getting through.

It's like a motor—it can be a very powerful motor, but if you can't get the electricity to the spark plugs, the machine just won't run.

The importance of the recognition of fatigue as a special symptom of MS extends far beyond that of the family and friends' understanding. It is also at the center of a controversy over the definition of MS for the purposes of social security disability benefit.

Thank you.

Chairman **Heinz**. Ms. Davy, thank you.

Now, each of you has told us that before you became disabled you worked.

Ms. Heiser, what was your job? Would you just repeat that briefly, what you were working in?

Ms. **Heiser**. I worked for an internist at Northwestern Memorial Hospital as his office nurse.

Chairman **Heinz**. Mr. Vance?

Mr. **Vance**. I have been handicapped all of my life. I have had several different jobs. I have done everything, when I was younger, from setting pins to driving a cab, but because of my handicap I was not hired for many——

Chairman **Heinz**. You were not hirable?

Mr. VANCE. Not for a lot of jobs, I probably could have handled before.

Chairman HEINZ. What was the most interesting job you were able to get?

Mr. VANCE. I would have to say night clerk and bookkeeper at a hotel.

Chairman HEINZ. Ms. Davy, would you—excuse me. I did not mean to interrupt a well-earned swallow of water.

Would you repeat your job that you worked on?

Ms. DAVY. Yes, I was a keypunch operator, and then I was supervisor of that particular data processing unit, and then keypunch operator again, in a less stressful part-time job than I had before.

Chairman HEINZ. Yes.

Well, with the exception of Mr. Vance, who had difficulty getting hired for work, the other two of you had very interesting occupations, not the kind of occupations that anyone would willingly give up, such as a supervisor at one point, as an office manager for a physician, in another case, and yet the Social Security Administration says that they were only terminating people who either do not want to work, or who are really able to work but do not know it.

Now, clearly all of you have wanted to work, you have all tried to work, you all would dearly love to be able to work. So we dismiss that reason.

Now, when you went to see the people from the State agency who administer the program—did they tell you what kind of work you could do?

Did they ever, Ms. Heiser, say what kind of work you could do?

Ms. HEISER. They said I should do sedentary work, and lift up—I could lift up to 20 pounds a day. What that meant, I had no idea.

Chairman HEINZ. Did they give you an example of a job?

Ms. HEISER. No, they did not.

Chairman HEINZ. Mr. Vance, did they tell you what you could do?

Mr. VANCE. Yes, the last job I had before I was disabled to the point where I could not work any more was the shuttle bus driving.

Now, since I went on social security I have had a shunt put in my head. I still continue to get the migraine headaches, but in their reasoning, which they sent me back in the letter, I was capable of going back to work as a busdriver, hauling passengers in a public conveyance.

There is two things wrong with that. No. 1, I would not do it, because I still have migraines, where I can black out, and not know what I am doing, and No. 2, I would not be able to get a chauffeur's license to drive. I have even given up my own driver's license, because I do not want to be the cause of somebody's accident.

Chairman HEINZ. Ms. Davy, what did they say that you could do?

Ms. DAVY. Well, the doctor's report was that I was capable of fine finger motion, and could lift, I believe, up to 10 pounds.

Chairman HEINZ. Did they tell you what job you would be hired for?

Ms. DAVY. Oh, no.

Chairman HEINZ. What did they tell you about a specific job? Did they give you any examples at all?

Ms. DAVY. No, they did not tell me at all what I could do.

Chairman HEINZ. Let me ask you all a different question. Here is Ms. Heiser, and your benefits were cut off——

Ms. HEISER. Yes, sir.

Chairman HEINZ. And you mentioned you had to hire a lawyer to get your rightfully earned benefits back.

Now, when you were reinstated, you got your back benefits, but you had no income during that period, and you mentioned that you had additional medical expenses. Were they reimbursed by medicare?

Ms. HEISER. Yes, they were.

Chairman HEINZ. Now, did your lawyer work for free?

Ms. HEISER. Yes, she did.

Chairman HEINZ. You were very fortunate.

Ms. HEISER. Yes, I was.

Chairman HEINZ. Because many of the lawyers who help reinstate people through the administrative law judge process charge a standard fee of 25 percent or more. Twenty-five percent seems to be about—I hope your attorney is not listening to this—25 percent or more of the reinstated benefits.

Mr. Vance, you did not need an attorney, is that right?

Mr. VANCE. I had a paralegal from the Legal Assistance Foundation of Cook County. I did need a paralegal for my judicial hearing.

Chairman HEINZ. Did you have any additional expenses that never got reimbursed by social security?

Mr. VANCE. No, my benefits have continued.

Now, this is a problem you run into a lot of times with people who are cut off, they do not know that if they file for an appeal or judicial hearing that they can also request that their benefits—I do not think now, but before that I could, because I started before the cutoff.

Chairman HEINZ. Up until about a week ago HHS had the authority to pay benefits through the adjudication.

Mr. VANCE. Yes, clear until the judge's decision.

Chairman HEINZ. Yes. Now, I want to ask about that, but I want to make a comment so no one misunderstands.

The payment of benefits after reconsideration is a relatively new phenomenon. It was put into effect in January of 1983. So people who were terminated prior to January of 1983 did not have that option, but I would like to ask you this. When they told you, or when you found out you could get those benefits, did they tell you anything else, as to what would happen to those benefits if you elected to take them and were not reinstated by the administrative law judge?

Mr. VANCE. They told me that I would be asked to repay them, but that if I could not, they would waive them.

Chairman HEINZ. Did that assist your peace of mind, knowing that?

Mr. VANCE. To some extent, yes, but let me tell you one thing, if it had not been for the fact I have done some volunteer work with a couple of handicapped—volunteering, not work. I volunteer on a hot line for disabled people.

I also put in 1 day or 2 days a week, for 3 or 4 hours, with the Spina Bifida Association, helping them on the phone and stuff like that. If it had not been for the fact that I knew all of this stuff, I might not have known to appeal and to ask for my benefits to continue at that time.

Chairman HEINZ. Ms. Davy, you got your benefits back. I do not remember for how long you lost them. Did you lose them at all at any point?

Ms. DAVY. Yes. However, I elected to have them continue. I had read my book, and it said that you could do this.

Chairman HEINZ. Did you have any additional out-of-pocket costs that you incurred to get to maintain your benefits, to win your case?

Ms. DAVY. No.

Chairman HEINZ. All right.

Senator Percy?

Senator PERCY. Mr. Chairman, I have no questions.

Ms. Davy has come to our Springfield office, we have worked with her on her case, and I had firsthand knowledge of it. I had not had firsthand knowledge of the other two cases, Mr. Vance and Ms. Heiser.

I just do not know when, in the 17 years I have heard witnesses, any who have been more impressive to me. All the statistics in the world are no replacement for personal human experiences. Your willingness to express your innermost thoughts and emotions will help, I think, a great many of us, and will also help the Social Security Administration in the work they carry out.

From what I have seen, SSA wants to do the right thing. They get bogged down with the pressure and the work requirements, and so forth, but I think this will help dramatize to them how one single case is impacted. You will not just be a statistic, you will be living examples of people who are doing the very best they can under the circumstances that have been certainly adversely affecting them.

Thank you very much.

Chairman HEINZ. I have just one last question of Ms. Heiser.

When you filed for reconsideration, you went to see someone, and they told you, in effect, that in their judgment you looked OK, or you had clearly improved. How did you go about having to prove that you had not clearly improved, and more importantly, why did they not believe you?

Ms. HEISER. Well, the letter that I received stating that I was no longer disabled, even though my past history was three open heart surgeries, social security in their letter of denial stated that according to their records I had had no heart attack, and therefore, what I had did not count.

Chairman HEINZ. They just ignored that part of your medical history?

Ms. HEISER. So the fact that I had had three open heart surgeries, that I am in fibrillation, that this valve is not working as well as it should——

Chairman HEINZ. The lesson, I suppose, that sheer logic, not commonsense, but sheer logic, would draw is that it would be better not to have open heart surgery, to go ahead and have a heart attack and die.

Ms. HEISER. Or die. It would be better.

Chairman Heinz. That would be the logic of that particular thing——

Ms. Heiser. As a matter of fact, I would just like to make one point. When I talked to the second adjudicator, and when they stopped my disability benefits, after the letter that I received in September 1982, I called Springfield, and I spoke to the gentleman, and I said to him, "What do I do, I am uninsurable. What do I do?" He said, "Get a job."

Chairman Heinz. My concern is that there are not just three of you, but there are tens of thousands, perhaps over 100,000, and maybe as many as 350,000 people who have had exactly the same experience as you have, and who have exactly the same range of real problems as you have.

We are talking about a system that has reviewed 1.1 million people, and there is virutally incontrovertible evidence based on studies that the General Accounting Office and the others have done for the Committee on Aging, that your cases indeed are typical of some 350,000 people, either who are in the pipeline now, some place between a reconsideration and adjudication, or who have had their benefits wrongfully denied.

Mr. Vance, how in reconsideration were you asked to prove that you were, indeed, fine?

Mr. Vance. I was asked to bring more information from my doctors, which I did.

Incidentally, if I may take just one more minute here, I have a letter here from my neurologist in Evanston, Dr. Vick, who is head of neurology at Evanston Hospital, Northwestern University, and also a professor of neurology.

It is written to Mr. Douglass at the Illinois State Department of Rehabilitation Services.

Chairman Heinz. With your permission, Mr. Vance, I would like to put the entire letter into the hearing record.

Mr. Vance. You have a copy of it.

[The letter referred to follows:]

Evanston Hospital

2650 Ridge Avenue
Evanston, Illinois 60201
312 492 2000

Division of Neurology
312 492 3976

May 20, 1983

Mr. Hewitt Douglass
State of Illinois
Dept. of Rehabilitation Services
Box 3842
Springfield, IL 62708

Re: Donald Vance
4349 N. Kenmore
Chicago, IL 60640
SS# 559-38-0332

Dear Mr. Douglass:

Your questioning the need for Mr. Vance to be on disability is truly outrageous. He has spina bifida with hydrocephalus and is incontinent of urine and feces, though, as an adult, has learned to deal with his incontinence to the extent that he can present himself adequately to the public. He can walk with special shoes (recently denied him as necessary!) and spends his days at the only work he is capable of, as a desk volunteer for the Spina Bifida Association.

If his detailed records have not been sent to your office any less than three times in recent years, I would be surprised. The matter is to the point of harassment of him, and the physicians who care for him.

I have advised Mr. Vance to submit a copy of this letter to his Congressman if the matter is not settled quickly. He is totally indigent and cannot afford a lawyer to assist him, but I can tell you that as a long-time patient of mine I will do everything I can to assure that he receives the sustenance and medical rights he deserves.

Yours very truly,

Nicholas A Vick

Nicholas A. Vick, M.D.

Professor of Neurology
Northwestern University Medical School
Head, Division of Neurology
Evanston Hospital

NAV:je

cc: Donald Vance

A Member of the McGaw Medical Center of Northwestern University

Chairman HEINZ. And what was the response of Social Security?

Mr. VANCE. They ignored this. They ignored this.

Chairman HEINZ. They just ignored it?

Mr. VANCE. As far as I can tell. It was never—when we went before Judge Stillerman in Evanston for the hearing, he was surprised at the thickness of my file, which was up to about 3 inches. My paralegal had gone back to 1974, and gotten all of the hospital records, of all of the times I had been in there for decubitus on the buttocks, and for nerve problems related to the spina bifida, and this surgery and the shunt and everything, and he had not seen any of that.

So that is why it is taking quite a while for him to make a decision on me.

Chairman HEINZ. Ms. Davy, I think in a way you did explain the peculiar nature of the multiple sclerosis disease, but so it is a little more understandable, do you have anything else to help us understand their either lack of attention to or unnecessary ignorance of afflicting diseases of people who are disabled, by the people who told you on reconsideration that you were really fit to work?

Ms. DAVY. Well, on the first doctor's examination, I thought she was a neurologist. Apparently she was not, or not a very good one, she did not know—I should not say that—she did not know very much about multiple sclerosis, and what it can do and does. It does not get better.

Chairman HEINZ. May I say to all three of you that you have been wonderful witnesses, spectacular examples of human courage. It is not easy to come before people you do not know, Senator Percy and myself—I guess one of you knows Senator Percy—much less a roomful of people and the press. We are deeply grateful to you for telling us your most intimate details of your life.

We thank you very much.

Mr. VANCE. Can I make one, just one final statement?

Chairman HEINZ. Yes.

Mr. VANCE. As the laws and the rules stand right now, we can be doing this again in 3 years. We are going to have to keep going back every 3 years to prove that——

Chairman HEINZ. It is my fear that the 3 years runs not from the time that the administrative law judge decides that you have been reinstated. I am afraid that the 3 years may actually run from the time that you received your first notice.

Mr. VANCE. Then I will say in 2 years.

Chairman HEINZ. But that is another issue which we need to ask the Social Security people about.

Senator Percy has already completed his questions.

Thank you all very much for being here. We appreciate it more than I can say.

I understand there are a number of people here today in the audience who contacted my staff and indicated they would like to testify. We are, as a committee, somewhat constrained by time, and we are not able to accommodate everybody who would like to testify. We will try and find a way to accommodate the taking of your testimony in a way where it can be submitted to the committee for the record.[1]

Indeed, it might be possible to get a recorder at the end, and we can take some verbal statements that will be part of the record.

Second, I would announce that this is the fourth hearing that the Committee on Aging has on this subject. Two of those four hearings have been devoted exclusively to the very serious and tragic problems of the review of the mentally disabled people who, as decided by a recent court decision, were, in fact, unfairly singled out by the Social Security Administration for the discontinuation of their benefits.

It is not a new subject to the committee, but we would welcome the taking of your testimony, and submissions at the conclusion of this part of the hearing.

We have four witnesses and one accompaniment. Mark Hudson, Zena Naiditch, Barbara Samuels who is accompanied by Joseph Antolin, and Tim Snyder. Please come forward and take your seats.

I apologize for the rather crowded condition of the platform. Do not become disabled by falling off the sides.

Before I ask Mr. Hudson to begin as our first witness, I would just, for Senator Percy's convenience, start identifying the fact that Mr. Hudson is here on behalf of the National Association of Disability Examiners.

Ms. Naiditch is here as the executive director of the Developmental Disabilities Protection and Advocacy Board.

Barbara Samuels is from the Northwestern University Legal Clinic and Mr. Snyder is director of programs, Access Living in Chicago.

Mr. Hudson, why do you not give us your testimony?

STATEMENT OF MARK C. HUDSON, INDIANAPOLIS, IND., REGIONAL DIRECTOR, NATIONAL ASSOCIATION OF DISABILITY EXAMINERS

Mr. HUDSON. Thank you, sir.

On behalf of the National Association of Disability Examiners—NADE—I welcome the opportunity to express our association's views on the social security disability program. I am the current regional director of the Great Lakes region of NADE. This region has a membership of approximately 525 individuals engaged in a wide variety of functions within the disability program of the States of Illinois, Indiana, Michigan, Minnesota, Ohio, and Wisconsin.

NADE is a professional association open to all persons involved in the evaluation of claims for disability benefits, in the public and private sector. The majority of our membership is in the State disability determination services who are adjudicating the disability claims for the Social Security Administration. Other members include attorneys, physicians, psychologists, and others involved in all aspects of disability evaluation. Our membership shares the public awareness to the problems existing in the implementation of the Social Security Administration disability insurance and supplemental income programs.

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[1] See appendix.

Since the inception of Public Law 96-265, also known as the 1980 Disability Amendments, there has been considerable outcry from the public due to the accelerated process by which the claims were being reviewed and by the high percentage of terminations that were being processed. After the accelerated continuing disability reviews—ACDR—were instituted in 1980, State agency termination rates ranged from 40 percent to 65 percent, some higher in some months. This was an alarming rate since the GAO study prior to 1980 gave an indication that approximately 20 percent, or one out of every five individuals who were on disability, did not belong on the disability rolls. After 1980, State agencies, however, were terminating benefits approximately at the rate of one out of every two, or about 50 percent.

After 1980, we found that administrative law judges were reversing these State agency terminations almost to the tune of 50 percent; 1981 and 1982 were very hard years on the staff of the disability determination assistance. They were receiving a majority of the adverse publicity for the high termination rates produced by the accelerated and periodic reviews and for the high reversal rates produced by the administrative law judges of these terminations.

This region was involved in a situation in December 1982 in which a Federal court in the State of Minnesota ruled against SSA because the administration was not applying the sequential evaluation process instituted for the determination of disability claims, in cases dealing with the mentally impaired. This region fully supported the action of the court. The Great Lakes Regional Board, directed me as regional director, to send a letter to then Commissioner Svahn, stating such support.

At this same time, legislation was passed, Public Law 97-455, which gave relief to those beneficiaries who were being ceased disability benefits. This law has two provisions which affected these recipients: (1) Temporarily provided for continuation of benefits through the administrative law judge hearing for those individuals terminated and appealing their cases. (2) Provided that an individual should be granted the opportunity for a face-to-face evidentiary hearing, during reconsideration of any decision that disability has ceased.

Initially, these hearing officer positions were to be Federal positions, but in October 1983 the Secretary of Health and Human Resources, Margaret Heckler, gave the States the option to hire State personnel to conduct the hearings, beginning in January 1984. It is my understanding that all but three of the States have opted to perform this function. In those States that have opted not to perform this function, Federal hearing officers will perform the duty.

These two steps taken by Congress were well received. However, the continuation of benefits timeframe in the provision has now expired. State agencies have been given instructions to begin ceasing benefits. The claimants have no opportunity for benefit continuation while the decision is being appealed. This situation is quite bothersome to a majority of us involved in the disability process. This can create havoc upon the recipient who has become economically dependent on social security. To stop benefits during an appeal procedure, in which cessation, as mentioned before, is reversed almost 50 percent of the time by an administrative law judge seems inhumane. I would urge you to restore the continuation provision on a permanent basis.

In December, Social Security imposed a moratorium on cessations until Congress took action on benefit continuation. This moratorium has now been lifted, but the claimants are to be told by letter at least 2 weeks in advance of the last check whether benefits will continue or not. For claimants given due process in February, this decision must be made by mid-April. This constant change in the application of due process over the past year has been dysfunctional to the adjudicative process. At one point States were giving predetermination notices for due process, then we were granting benefit continuance for due process. Now States are being told to once again use predetermination notices, then hopefully we will again change to benefit continuances. All of these changes in the application of due process have occurred over a very short period of time.

The opportunity for a face-to-face evidentiary hearing during the reconsideration of a decision that disability has ceased is an excellent step in removing some of the problems facing claimants. I am personally involved in the planning for this project in my own State, Indiana, and am excited about the possible results of these hearings. I believe they can act as an expeditious and fair process. There are now provisions in the current bill before Congress, H.R. 4170, to extend this hearing process to the initial level of disability for these claimants who are initially applying for benefits. If this legislation is enacted, five States will experiment with this project. I would urge this to be expanded to all the States, and not as an experiment, but rather as a permanent procedure.

By establishing such hearings we can create an opportunity to view the claimant sooner in the disability process. We can alleviate the wait that now is a part of the administrative law judge hearing. This can create a relief to those individuals who have recently become disabled.

The Social Security Administration is now in the midst of a problem to the degree that I have never before witnessed. I am referring to the different criteria being used to determine continuation of benefits. As of the most recent count, 28 States, either due to a court decision, or through their own initiative, are using a criteria different than the one Social Security has established in determining if benefits continue. A national program such as the social security disability program cannot afford to be caught in such a situation. A determination of disability should not be made, in a national program, on the basis of residence.

In this region, the States of Illinois, Michigan, and Ohio have determined medical improvement to be the criteria utilized in determining eligibility. The States of Indiana, Minnesota, and Wisconsin are continuing to use the standard set out in the regulations, for example, disability based on current condition only. Certainly this needs to be addressed.

NADE is aware that the current Levin-Cohen bill has provisions that State medical improvement is the criteria to be utilized in determining continued benefits except when: There are new diagnostic techniques available, the claimant is engaging in SGA, there have been medical and vocational advancements, when the original decision was either erroneous or fraudulent.

The Great Lakes region of NADE has carefully studied the subject. While we support this medical improvement package we have authored an additional solution which has been accepted by the NADE board of directors.

The solution this region feels should be implemented on a national basis has two proposals: (1) Beneficiaries, aged 55 years and older, who have been on the disability rolls for 5 years or longer, should be continued, unless there is specific evidence of medical improvement. (2) Beneficiaries, age 50 years or more, and who have not demonstrated the ability to perform past work should be continued.

These proposals consider the reliance many disabled persons have come to place on the disability benefits they receive, as well as the adverse effect longevity on the rolls place in a person's successful return to the work force. All of the aforementioned would provide equity in evaluation and less harshness than the present system, but maintain the integrity and purpose of the disability insurance program.

There has been some improvement in the CDR process in the past year. The moratorium on mental impairments is a fine example. Yet there is more that can be done. I believe we need more of a comprehensive reform. It is of utmost importance that we establish a fair and humane definition of disability which will be utilized in all States. The program must establish a uniform definition of disability and apply this one definition nationally.

In this same vein we do not feel Social Security should acquiesce to court decisions. If this were to happen a national program could have nine different administrations. The Secretary should appeal certain court decisions to the Supreme Court. We do not recommend application of circuit court decisions to only these States in that circuit because it would not accomplish national uniformity.

There is one final area that I would like to touch upon. This area has caused serious outcry over the past few years. I am talking about the handling of mental impairments by the social security disability program. This outcry was highlighted by the court case in Minnesota. There has been changes in the handling of mental impairments by the Social Security Administration. The American Psychiatric Association has been working closely with Social Security to revise the listing of impairments.

It is my understanding that new criteria will be out within 45 days, and at that point will be published for comment in the Federal Register. I would urge careful monitoring of this procedure. This disabled population needs to be treated as fairly as possible. We must keep in mind that the claims involving a mental impairment are the most difficult to evaluate.

The moratorium on mental impairments has brought relief to these individuals who are mentally impaired and currently on the rolls. However, what about those who are not on the rolls? Social Security needs to take careful but swift steps toward an equitable and reasonable approach to the evaluation of these individuals who suffer a mental impairment.

Social Security has stated legislative reform is not required at this time. It believes that a top to bottom review of policy and face-to-face interviews can provide necessary action that needs to be taken.

While NADE applauds these actions, we do not feel they adequately address all the problems facing social security. Further steps need to be taken that can provide an equitable and uniform package.

In summary, NADE recognizes a need for legislative action to improve the administration of the current social security disability program. At the least we must issue legislation to:

First, allow for the continuance of benefits through the ALJ level for those who have been terminated.

Second, continue to afford an individual the opportunity for a face-to-face hearing prior to termination of benefits and to extend this to the initial level for new disability applications.

Third, establish a uniform criteria to be utilized in determining continued eligibility.

Fourth, consider NADE's proposal which considers the effects of longevity on the rolls and the reliance many disabled persons have come to place on social security.

Fifth, support the concept that the Secretary appeal certain decisions to the Supreme Court.

Sixth, enact, swiftly but carefully, criteria for mental impairments.

Thank you, Mr. Chairman and committee members for the opportunity you have provided the National Association of Disability Examiners to present this testimony.

Chairman HEINZ. Mr. Hudson, thank you very much for your excellent testimony.

And, Ms. Naiditch?

Ms. NAIDITCH. Thank you, Mr. Chairman. I would like to submit my statement for the record.

Chairman HEINZ. Very well. Thank you very much, Ms. Naiditch.

[The statement of Ms. Naiditch follows:]

STATEMENT OF ZENA NAIDITCH, EXECUTIVE DIRECTOR, DEVELOPMENTAL DISABILITIES PROTECTION AND ADVOCACY BOARD, CHICAGO, ILL.

Mr. Chairman and members of the committee, I appreciate your invitation to testify before you today on the social security disability programs (SSI and SSDI); the impact of recently implemented changes in the programs on disabled persons in Illinois; and the need for congressional action in this area.

I am executive director of the Developmental Disabilities Protection and Advocacy Board, a State agency established by Executive Order in accordance with the Developmental Disabilities Assistance and Bill of Rights Act (Public Law 95-602). The board is mandated to advocate and protect the rights of developmentally disabled persons in Illinois. The board is representative of disabled persons, family members, and others with an interest in the field of developmental disabilities.

Last year, the board identified protection of the SSI and SSDI benefits of developmentally disabled persons as a priority, after receiving numerous calls for assistance with individual cases; reports from local health and social service agencies about their clients' problems with the programs; and, requests for training on how to assist clients in appealing unfair denial or termination of benefits.

Perhaps the impact of recently enacted changes in the programs is best understood by listening to the stories of disabled persons who have experienced hardship. Persons whose medical condition is unchanged and who have come to rely and depend upon their monthly SSI and/or SSDI payments to meet basic living expenses only to receive notices from Social Security stating that review of their case shows that they are no longer disabled and can return to work.

My purpose, however, is to provide the committee with an overview of what has happened to disabled persons in Illinois. Analysis of State data on the SSI and SSDI programs (provided by the Bureau of Disability Adjudication, Illinois DoRS, 2/15/84) during fiscal years 1982 and 1983 (this is a duplicative count) shows that:

Most persons initially applying for benefits were denied (24 percent allowance rate, 67 percent denial rate, and 9 percent no decisions; total of 126,000 denials).

Approximately 40 percent of initial denials appeal to the reconsideration level.

Most appeals to reconsideration were not reversed (13 percent allowances, 78 percent denials, 9 percent no decisions. Total of 53,000 denials) (includes reconsideration for initial denials and SSDI persons who appealed an unfavorable CDR decision by requesting reconsideration).

For initial CDR's over 40 percent of those examined received cessation notices (47 percent allowed, 41 percent ceased, and 12 percent no decision; total of 18,000 cessations).

National data (from the Social Security Forum, November 1983, vol. 5, No. 12, National Organization of Social Security Claimants Representatives) shows that a full 53 percent of all cases appealed to an ALJ hearing (includes other than SSI/DI cases) were allowed in fiscal year 1982. Data on CDR's documents an even higher reversal rate: a full 77 percent of the persons terminated were reinstated at the ALJ level between April 1981 and August 1982.

The significant differences in approval/denial rates at various stages of the application and appeals process—particularly between reconsideration and the ALJ—can be attributed to several factors, including these:

The medical evidence and other records are more complete by the time the case goes before the ALJ.

Many claimants secure assistance in preparing and presenting their case before the ALJ from an advocate or lawyer and they can exercise many due process rights at the hearing.

The judges are relatively independent of SSA and the disability standard they apply is the law (statutes and regulations), but not necessarily the SSA program operations manual system (POMS); and

The judge meets face-to-face with the claimant and, if the diability is "visible," in some cases he will be able to see that the claimant's condition prevents him from working.

So, what has happened to all the disabled persons whose benefits were denied or terminated? Although reliable statewide data is not available at this time, the board has collected information and data from various State and local agencies and organizations. This information suggests that some truly eligible disabled persons, particularly those with mental impairments, never appeal a denial or termination of benefits because they do not fully understand their rights and have no one to assist them with the process.

Others may appeal an initial denial to reconsideration but give up when they receive notice that the original decision still stands; this also appears to happen in SSDI termination cases that go to reconsideration on appeal.

Those not fortunate enough to successfully appeal their cases on their own, or secure necessary assistance will be forced to turn to already overburdened State and local health, social service, and welfare programs.

Many will experience a significant reduction in their standard of living when they are terminated from the Federal SSA program and enter State/local programs. For example, an SSI recipient receives $314/month plus medicaid coverage. If he enters the Illinois Department of Public Aid's general assistance program he gets $144/month and very limited medical coverage (e.g., maximum hospitalization payment of $500/year).

Some disabled persons living relatively independently in the community may seek admission to a medicaid-covered residential setting (e.g., nursing home) when their benefits are terminated.

In response, the board has taken several actions aimed at helping disabled persons to cope with the current situation. These include:

Consumer rights handbook. We are publishing a free consumer rights handbook titled "How to Secure and Protect Your Social Security Disability Benefits (SSI and SSDI)."

Training program. We are sponsoring free, statewide training sessions for advocates, consumer/parent groups, service providers, and professionals and community organizations. In the first four sessions, 250 persons were trained. Two more sessions are scheduled for the Chicago area and additional sessions are being planned throughout the State.

Assistance on individual cases. Through our regional offices and contracts with legal assistance offices, the board has helped approximately 200 developmentally disabled persons who required assistance in appealing their cases. Our experience is that the vast majority win at the ALJ level.

Facilitate involvement by the private bar. The board is working in the private bar to develop strategies aimed at increasing their involvement with SSI and SSDI cases.

Study and make policy recommendations. The board continues to examine specific issues related to the fair and equitable administration of the programs and make recommendations.

These are short-term, stopgap measures aimed at controlling the current crisis. They have protected the benefits of some, but cannot possibly prevent the unfair denial or termination of benefits to the thousands of persons in Illinois involved with the application and appeals process each year.

Lifting of the Federal and State moritorium at this time would cause hardship for Illinois' disabled citizens. The State Bureau of Disability Adjudication Services estimates that 400 to 600 persons would begin receiving termination notices. Furthermore, those on the SSDI program would not be eligible for continuation of benefits pending appeal to the ALJ level (since Congress did not pass emergency legislation in this area).

On behalf of disabled persons in Illinois, the board urges:

Secretary Heckler, U.S. Department of Health and Human Services, to continue the Federal moritorium until further reform of the SSI and SSDI programs has been achieved and that she work with Congress towards the development and passage of reform legislation.

Secretary Heckler to establish a national task panel to regularly review proposed changes in the statutes, regulations, and policies governing the SSI and SSDI programs and that it be given the authority to undertake studies on its own initiative and to make recommendations. Issues the task panel should address include: Conduct an evaluation of the face-to-face interviews; review the existing POMS and recommend needed revisions; identify ways to ensure that complete records are collected and used by states' DDSs in making decisions on initial applications, reconsideration and termination cases; and propose revisions in the mental impairment listings. Membership on the task panel should include representation from the NGA; an economist; a public interest attorney; a vocational specialist; psychologist/psychiatrist with an expertise in mental impairments; a professional with an expertise in MR and other developmental and physical disabilities; physicians (e.g., orthopedic, internal medicine, cardiology); and representatives of national disability advocacy groups.

Congress pass legislation that includes the following provisions: Establishes a medical improvement standard before benefits can be terminated; insures on a permanent basis that all SSDI and SSI beneficiaries receiving termination notices be allowed to have their benefits continue through the ALJ level of the appeal process (SSA has not demonstrated that introducing face-to-face interviews at reconsideration will significantly alter the outcome at reconsideration); requires SSA to apply decisions of the courts of appeal or appeal those decisions with which it disagrees; and provide for a temporary moritorium on all mental impairment reviews until such time as the listings for mental impairment have been revised.

There is broad support for comprehensive, reform legislation. The board urges you to act on the requests of the National Governor's Association, Advocacy organizations, service providers and professional associations and others who recognize the need for statutory reform to protect eligible disabled persons from the unfair denial or termination of benefits to which they are entitled.

Mr. Chairman, I thank you for giving the board the opportunity to testify before the committee.

Chairman HEINZ. Barbara Samuels?

STATEMENT OF BARBARA SAMUELS, CHICAGO, ILL., NORTHWESTERN UNIVERSITY LEGAL CLINIC; ACCOMPANIED BY JOSEPH ANTOLIN, LEGAL ASSISTANCE FOUNDATION OF CHICAGO, ILL.

Ms. **Samuels.** I am with the Northwestern University Legal Clinic, where I supervise a disability project which involves student representation of disability claimants, many of whom, but not all of whom are termination cases.

Before that I was with the Legal Assistance Foundation of Chicago, which is the legal services funded program. So I have, over the years, probably handled, supervised, or given counsel on 500 or more disability cases.

I would like to do something a little bit different than the other speakers today, and that is to build on what a prior witness testified to earlier. I would like to use the case of Vera Heiser as a case study—I was her attorney—because I think that it represents or demonstrates some general problems with the adjudication of the cases, and raises questions about what comprehensive legislation can achieve.

As Ms. Heiser said, she was found disabled in 1969, as a result of rheumatic heart disease. She was initially notified that they were considering termination of her case in December 1981. At that point social security had obtained no evidence at all, there was nothing in the file. She received a 10-day letter, telling her she could submit evidence, and she did so.

She submitted a letter from her treating surgeon, and in that letter the treating surgeon said, and I quote:

> I take serious exception to social security's evaluation of Ms. Heiser's condition. She has suffered rheumatic and valvular heart disease for a long time. She is currently recovering from her third open heart surgery. She suffers from serious arrhythmia, extreme shortness of breath, migraine headaches and if she returned to work of any kind, it would cause her great difficulty.

Then he went on to say—and this is underlined—"Ms. Heiser is not a malingerer."

The initial decision to terminate her was issued in September of 1982, and about that surgeon's letter, all social security said was—and again I quote—"it gives no new objective medical findings to substantiate a disability."

So despite that evidence, social security concluded that the claimant did not meet the listing, any listing of impairment, which is automatic proof of a disability, and that she had the capacity to return to her past work as a nurse.

Social security had made no effort to obtain hospital reports, if they thought that objective findings were necessary. They did not consider a medical improvement under any rubric. Indeed, they did not consider anything but the medical listings. They did not consider the issue of severity, and obviously gave no weight to the treating physician's opinion or report. They did not consider subjective complaints. They certainly did not consider the vocational question of what is required to perform the duties of a nurse.

Ms. Heiser appropriately asked for a reconsideration, and she submitted additional reports, reports from her treating cardiologist, and from her thoracic surgeon.

The treating cardiologist explained, at great length, the history of her disease, including her surgeries, her allergic reactions to drugs that might control her condition, but could not be found to control her condition; her recent uncontrolled arrythma and other postsurgical complications, and that the client was a very fragile person, who was readily fatigued, unable even to do housework, had chest pains, shortness of breath, palpitations, and that these were demonstrated by electrocardiograms and X-rays.

He further characterized her impairment on the classification system universally employed by the American Heart Association. He classified her as 3-B, and indicated that that meant restriction from any type of physical activity, other than walking and daily activity of living.

The thoracic surgeon, in his additional report noted that she experienced repeated blood clots, both in her brain and in her legs, that her EEG's were abnormal, and he concluded that she was not able to do any work.

In response to all of this, social security, interestingly enough, sent the client to see a psychiatrist. The psychiatrist reported that she was, indeed, severely depressed, that she had what he considered a major depression, and that it impaired her ability to concentrate.

Social security had this psychiatric report reviewed by one of its physicians in Springfield, who happened not to be a psychiatrist, but an internist. This internist concluded that the client could do simple unskilled work.

You asked Ms. Heiser earlier what kind of work they suggested she could do. A vocational assessment based on the interpretation by social security's internist was obtained by social security and the conclusion was—and this is something that Ms. Heiser could not have known, because she has never seen her file—"The simple unskilled work that Ms. Heiser could do was as a fishing reel assembler, or a plastic design applier in the shoe industry."

So despite noting that Ms. Heiser suffered from rheumatic heart disease, that she had had three open heart surgeries, that she had had three episodes of blood clots in the brain and in the legs, that she suffered from a major depression, social security submitted, or issued a reconsideration termination notice in January 1983.

At that point social security had again, for a second time, made precisely the same mistakes that it had made before. It did not give any weight to the treating doctor's evidence or his opinion. It did not look at the objective evidence, nor at the subjective evidence. The client's allergic reactions to medications were not looked at at all, and they made no vocational assessment, and they certainly did not apply a medical improvement standard.

In May 1983, an administrative law judge reversed the decision of the reconsideration people without a hearing, based on precisely the same evidence properly evaluated, that had been before the reconsideration folks.

So what does the Heiser case demonstrate? I think it demonstrates four separate things. That no matter how well a client cooperates, or indeed, the client's doctors cooperate, or how complete and compelling the medical evidence is, social security ignores it.

Second, in the absence of an improvement standard, social security's decisions tend to be almost totally arbitrary and lawless. At most, social security was considering the listing of impairments, no assessment was made of severity, subjective symptoms, pain, fatigue, shortness of breath, the documented physicians' opinions, or vocational factors.

Social security appears to have made the Heiser decision based solely on consideration of a psychiatric evaluation which was not essential to the client's case.

At the reconsideration stage SSA had more documentation in the Heiser case than it has in most cases, and yet that documentation meant nothing, it rubber stamped the initial termination.

An administrative law judge reversed and reinstated Ms. Heiser based on the same evidence that the reconsideration people had. Well, what does that mean in terms of comprehensive legislation?

First, I think it means that we have to stop the mass terminations. If fewer terminations occur, then the chance is, the hope is that there will be a better chance that they are done right.

Second, we must have a medical improvement standard, make social security justify terminations on an ascertainable and rational basis.

Third, we have got to require uniform standards throughout the adjudication process, standards which properly reflect the statutory requirements, which include consideration of medical and vocational factors, subjective and objective evidence, age, education and the realities of past work.

Additionally, we must require social security to publish its regulations, and not to use informally created and unpublished rules.

Fourth, the reconsideration stage is a pointless effort. It is an effort, an exercise in futility. It should not be implemented in the new face-to-face reconsiderations.

The face-to-face reconsiderations, as they have been designed by social security, will be expensive, they will be wasteful, they will be time consuming, they will be a sham of due process. It is an elaborate but meaningless level of review. If there are face-to-face interviews within the State administration, they should be done at the initial termination stage. There is no point in having that second level of review, under any circumstances.

Finally, the additional reason not to institute this reconsideration stage will be that I think it will further discourage appeals, and cause more hardships. There is no reason to suggest to somebody who does not understand the system in the first place that they are going to get a chance to talk to somebody directly who will make a decision, and then when they lose, suggest that they go on to do the same thing with an administrative law judge who they do not know is more likely to do it right.

Appeals from termination should therefore be directly from the initial decision, to an administrative law judge hearing, which is precisely the way it is done now for SSI termination cases.

And, finally, I think the benefits pending appeal must be paid through the ALJ decision. That is not an exhaustive list of the kinds of legislative points that I think need to be made, but I certainly think that the need for these is documented by what happened to Ms. Heiser.

Thank you.

Chairman **Heinz**. Ms. Samuels, thank you very much.

[Material related to Vera Heiser follows:]

NORTHWESTERN MEDICAL FACULTY FOUNDATION, INC.

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Renee S. Hartz, M.D.

September 15, 1982

Mr. Laurence Przybylski
Bureau of Disability Adjudication Services
P.O. Box 3842
Springfield, IL 62708

Re: Mrs. Vera Heiser

Dear Mr. Przybylski:

I am writing you about Vera Heiser #367-40-8244, who I operated on 5½ years ago and again in October of 1981. She continues to be followed by Dr. James Talano; an attending cardiologist at Northwestern Memorial Hospital. Mrs. Heiser recently called me because she was informed that her disability was being discontinued because of her absence of chest pain and the fact that she had not had a heart attack. It also was stated that she could stand and walk through a six to eight hour day; because of these considerations she could return to work.

I take serious exception with that evaluation of Mrs. Heiser's condition. She is just now recovering from her third major cardiac surgical procedure. She has migrane headaches, and continues with severe difficulty due to her atrial fibrillation which, when it becomes rapid, causes extreme dyspnea on exertion and distress. She needs to be maintained on life-long anti-coagulation with Coumadin and she continues on digitalis, diuretics and potassium supplementation. I think that if she would return to any kind of employment, there's a good chance that the atrial fibrillation would cause great difficulties, so I certainly do not think she is capable of working full-time as a nurse or even as a receptionist in a physcian's office.

Dr. Talano is presently disabled with a fractured pelvis and will be out for the next six to eight weeks; I am certain that he concurs with me in this opinion, but perhaps you might want to contact him when he is back in good health. I hope this will be of assistance to you, and I sincerely hope that you will re-evaluate Mrs. Heiser's Claim. This woman is not [illegible] and she has suffered the ravages of rheumatic fever and valvular heart [illegible] for a long time. If she could return to work, I'm quite certain that [illegible] would do so. If you have any further questions about Mrs. Heiser, [illegible] don't hesitate to contact me.

Sincerely yours,

LMichaelis

Lawrence L. Michaelis, M.D.
Professor of Surgery
Chief, Division of Cardiothoracic Surgery
Northwestern University Medical School

LLM/clc

cc: James Talano, M.D.
✓Mrs. Vera Heiser

NORTHWESTERN UNIVERSITY

CHICAGO, ILLINOIS

JAMES V. TALANO M.D.
THE MEDICAL SCHOOL
ASSOCIATE PROFESSOR OF MEDICINE
CHIEF, CARDIAC GRAPHICS LABORATORY
DEPARTMENT OF MEDICINE

REPLY TO
NORTHWESTERN MEMORIAL HOSPITAL
WESLEY PAVILION — SUITE [illegible]
SUPERIOR AND FAIRBANKS COURT
CHICAGO, ILLINOIS 60611
(312) [illegible]

September 25, 1982

Mr. Lawrence Przybylski
Bureau of Disability
Adjudication Service
P. O. Box 3842
Springfield, Illinois 62708

Re: Mrs. Vera Heiser
608 Plainfield Road
Darien, Illinois 60559
Social Security No. 367-40-8244

Dear Mr. Przybylski:

I am sorry that we could not communicate via telephone after our various tries. I am writing to you about Vera Heiser, a patient whom I have followed since 1977. As you know, her primary problem is that she has rheumatic heart disease with recurrent rheumatic fever; she has had rheumatic mitral valve disease and aortic valve disease. She has undergone three open heart operations; the second one in 1976 for a porcine mitral valve replacement. From 1976 until now she continued to have recurrent episodes of paroxysmal atrial fibrillation with a very rapid ventricular response. She was tried on multiple antiarrhythmic agents and developed severe allergic reactions to them, including lupus erythematosus, pericarditis, arthritis, pruritis, positive LE preps. She had been hospitalized for steroid treatment because of her severe reaction to antiarrhythmic therapy.

From 1976 until 1981, she continued to have difficulty with a paravalvular mitral regurgitation which prevented her from returning to her previous employment. She is an extremely fragile patient in that she is allergic to many drugs and consequently cannot take antiarrhythmic agents for control of her ventricular response. In fact, we've had to put her on several experimental drugs in order to control her heart rate.

Last year she again underwent a third open heart operation for mitral valve replacement with a Starr-Edwards mitral valve. Her postoperative course is complicated by persistence of pleuritic chest pain in the area of the incision, rapid atrial fibrillation, severe migraine headaches; these complications are unresponsive to the usual forms of therapy. She has tried new pain medication as well as antiarrhythmic medication and has developed rashes, arthalgias, pleuritis, thrombocytopenia, and chronic hemolytic anemia.

A MEMBER OF THE NORTHWESTERN UNIVERSITY—McGAW MEDICAL CENTER

Page Two
Re: Mrs. Vera Heiser

She continues to be disabled because of her pleuritic chest pain and her rapid atrial fibrillation which is not controlled on medical therapy. During the episodes of rapid atrial fibrillation, she becomes fatigued, dyspneic, and is not able to perform her household activities. For example, using a vacuum cleaner causes her severe dyspnea and palpitations. She must stop before continuing to proceed with her work.

I take exception with your evaluation of Mrs. Heiser's condition. You state that she has not had a heart attack or that she has absence of chest pain. It is unlikely that she would have a heart attack because she does not have coronary artery disease. She continues to have pleuritic chest pain in the areas of incision. She is severely limited by her atrial fibrillation which does not respond to conventional or experimental medication. Her ventricular response is such that she quickly becomes fatigued and dyspneic with very little physical activity. She is restricted from lifting greater than 20lbs., she is restricted from any job in which she is on her feet more than 2-3 hours. As her physician, I would find that she is unable to perform her duties as a nurse or nurse's aide for any period of time. Mrs. Heiser will continue to require anticoagulants and will need to be monitored very closely with prothrombin times. She is on various forms of medication to control her heart rate and ventricular response.

Given the above information, it is my very firm medical opinion that she is not a candidate for any form of employment. She needs assistance to perform her usual housework; her arrhythmia is such that it can worsen at any time, requiring that she promptly return to bed.

In summary then, my opinion is that Mrs. Vera Heiser has organic heart disease. Its etiology is rheumatic valvular heart disease; manifestation is mitral regurgitation and aortic regurgitation; presently she has a Starr-Edwards cage ball mitral valve replacement. Physiologically, she has atrial fibrillation with a very rapid ventricular response, relatively unchanged by medical therapy: American Heart Association classification is 3B, restricted from any type of employment or physical activity other than walking and her daily activities of living.

If I can be of any further help in your assessment of Mrs. Heiser, I would be happy to do so. I would strongly recommend that you re-evaluate her claim in light of this information, since we have a patient here who has been fortunate to survive three open heart operations and not live an armchair existence. If there is any need for further questions or documentation of the above statements, I would be happy to provide you with such information including a cardiac catheterization report from her last operation to substantiate our claim.

Sincerely yours,

James V. Talano, M.D.
JVT/peg

GRACE LUTHERAN CHURCH
3313 HAZEL LANE
HAZEL CREST, ILLINOIS 60429

Mr. Lawrence Przybylski
Bureau of Disability Adjudication Services
P.O. Box 3842
Springfield, Illinois 62708

Dear Sir:

I am writing in regard to Mrs. Vera Heiser, 608 Plainfield Road, Darien, Illinois, Social Security number 367-40-8244. I have known Mrs. Heiser for eleven years, both as her pastor and, more recently, as a close personal friend. I understand that she recently received a letter from you, stating that her benefits were going to be withheld because she has been classified as being physically able to return to work.

I would first of all like to say that, as one person who is currently paying into the benefits that are being distributed, that I am very happy to see that efforts are being made to eliminate waste, fraud and corruption. However, I must go on record as saying as emphatically as possible that a serious error has been made in the case of Mrs. Heiser.

In the eleven years that I have known and ministered to her, she has undergone three sessions of open heart surgery, thrown three clots to her brain, suffers from arthritis of the sternum and of the spine, and has counseled with me and with a psychiatrist on the subject of her mortality. In addition, she is subject to severe migraine headaches and her heart is fibrillating constantly, both of these conditions worsening with stress and worry. This present situation has provided abundant measures of both.

It seems to me that if this decision is not quickly reversed, Mrs. Heiser is in a no-win situation: due to the state of her health, she does not have the physical stamina to maintain a job, and without Social Security, she finds herself with no health care benefits and is virtually uninsurable. This is a situation that no citizen of this nation should ever find herself/himself in. I ask that you once again review her records, contace her many doctors to corroborate what I have said here, and reinstate her benefits with all due speed. She needs them, she deserves them, and she has suffered enough.

Sincerely,

Rev. Kenneth S. Hahn
Grace Lutheran Church
3313 Hazel Lane
Hazel Crest, Illinois 60429

cc: President Reagan, Senator Percy,
Senator Dixon

REVEREND KENNETH S. HAHN OFFICE 335-1597 HOME 957-1091

Chairman HEINZ. Mr. Snyder?

Excuse me. Wait, Mr. Snyder. I apologize. I forgot to call on Mr. Antolin, who is Ms. Samuel's——

Ms. SAMUELS. He is assisting me.

Chairman HEINZ. He is assisting Ms. Samuels, but I would not think with that testimony you would need any assistance, whatsoever.

Mr. ANTOLIN. The only points I would like to make are a little different. The first is that we have submitted a document written by Ms. Samuels, myself, Deborah Spector, who is a private attorney, whose practice is almost exclusively social security disability cases, and who sits as chairperson—chairman of the Chicago Bar Association's Social Security Roundtable, and Christine Naper, who is another social security specialist at the Legal Assistance Foundation. It is a comprehensive review of many of the issues that are addressed, both by the Heckler reforms and the administrative process.

We would like to submit that as part of the record.

Chairman HEINZ. Without objection that will be submitted as part of the record.[1]

Mr. ANTOLIN. The only point I would like to make is, when we were contacted—when I was contacted about these hearings, the question was asked, what have the Heckler reforms done? What is our reaction to them?

In short, I think, from what has been testified about, the Heckler reforms were too little, too late. There was a moratorium imposed on mental impairments after most of the mentally impaired were terminated, and were already in the review process.

In addition, the mental impairment moratorium does not affect those individuals who have a combination of a physical and a mental impairment. They continue to go through the process under what is a standard that has been declared illegal in this region.

Medical improvement has not been adopted, with the result that our State agency has been finding itself in a conflict with Social Security, causing the Governor to impose a moratorium on one level, causing the Legal Assistance Foundation and other advocates to file a class action suit on another level, because the court of appeals in this State has said that medical improvement is the standard Social Security must show before it can terminate.

Anyway, there is another problem that has been—that has resulted in a class suit in this State, and that is that a huge percentage of the terminations are terminations for a not severe denial—a not severe impairment.

Not severe is one of the steps in the sequential evaluation process which is abused. It makes no sense given the statutory mandate which requires consideration of a person's work experience, and their age and educational level. The severity step is not how severely impaired are you given all those factors, it is how severely impaired are you medically, without consideration of your age, education, your work experience, your pain, and other factors that are necessary for a determination of disability, and it is used frequently to deny benefits to people who have a complicated case that is not easily evaluated.

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[1] See appendix.

To be perfectly honest, the severity step, as it exists in the regulations, should be outlawed by Congress, because it, in fact, serves no purpose. It does not aid in administrative efficiency.

The rest of the steps of the sequential process will provide a full evaluation of someone's capability to return to work or not.

Finally, you have asked several of the witnesses who are appealing denials what out-of-pocket costs they had. Frequently none of them in fact had any. However, it has been the experience of the agency of the Legal Services Corporation here that we frequently have to arrange for consultative exams. The private attorneys I know frequently have to arrange for those also to get the correct impairment evaluated by a specialist, trained to evaluate that particular kind of impairment.

That is something that should not be incumbent upon the individual, but it is something that we frequently experience having to do.

The last point is aid paid pending during an appeal is just an absolute essential. In this State, in Cook County, which receives general assistance, a recipient will not get any medical coverage, will not get any drugs, and will receive $144, which is less than half of what the State had determined is necessary to live as a single individual, once they are cut off from their title II benefits or SSI, and that is tantamount to killing the disabled individual.

I have nothing further to add.

Chairman HEINZ. Mr. Antolin, thank you very much.

Mr. Snyder?

Mr. SNYDER. My name is Timothy Snyder. I am director of programs, Access Living of Metropolitan Chicago.

I would like to submit my prepared statement for the record.

[The statement of Mr. Snyder follows:]

STATEMENT OF TIMOTHY H. SNYDER, DIRECTOR OF PROGRAMS, ACCESS LIVING OF METROPOLITAN CHICAGO, ILL.

Access Living is an independent living center serving the needs of persons with disabilities in the Chicago metropolitan area. The overwhelming majority of our clients, certainly no less than 98 percent, receive either social security disability insurance or supplemental security income payments as their only source of income, and medicare or medicaid under Social Security Administration eligibility as their only source of medical insurance.

Our concern is not with the concept of performing continuing disability investigation. We understand the need for these investigations to be completed in a routine, timely manner. However, when these investigations are undertaken with the express purpose of saving $250 million in fiscal 1982, $600 million in fiscal 1983 and $850 million in fiscal 1984,[1] it would appear to the casual observer that "a percentage of disability recipients have been targeted for elimination from the disability rolls."

The pressure appears to be on administrative law judges and Social Security Administration personnel to quickly produce a substantial reduction in disability rolls consistent with administration policy. For example, Social Security Administration has targeted for review 65 administrative law judges who have the highest rate of findings that continue disability benefits.[2] Only findings in favor of beneficiaries are being reviewed, not decisions terminating benefits. Similarly, Social Security Administration is routinely reviewing 35 percent of decisions of State agency personnel in favor of beneficiaries, while only 5 to 7 percent of benefit terminations are reviewed.[3]

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[1] Statement of Howard Metzenbaum, Democrat-Ohio, taken from the debate on the Levin-Cohen amendment.

[2] Jan. 7, 1982 memo from Louis B. Hays, Associate Commissioner of Office of Hearings and Appeals, SSA, to all administrative law judges.

It appears that there was or is a preconceived game plan to categorically eliminate a percentage of disability recipients from the Social Security Administration disability rolls and that this plan is unfair, unproductive and discriminatory.

Access Living supports legislation reforming the social security program which would, in effect, bring back to balance the continuing disability investigation procedure. The following is a listing of reforms which are supported by Access Living.

SECTION 101: STANDARD OF REVIEW

Disability benefits can be terminated only with clear and convincing evidence of (a) significant medical improvement which enables the person to perform substantial gainful activity (SGA); or (b) new medical evidence and a new assessment of residual function capacity (RFC) showing that the person has benefited from advances in medical or vocational therapy or technology, making him able to perform SGA; or (c) the prior decision was clearly erroneous or fraudulently obtained; or (d) the person is currently performing substantial gainful activity.

SECTION 102: MULTIPLE IMPAIRMENTS

The combined effects of impairments may be considered in determining whether someone can work, even if none of the impairments, considered separately, is severe.

SECTION 103: EVALUATION OF PAIN

Debilitating pain or other symptoms such as dizziness and numbness may lead to a finding of disability, even when diagnostic techniques fail to fully explain the extent. Subjective evidence of disabling pain and other similar symptoms, if corroborated by the patient's behavior and by family and friends, could be sufficient.

SECTION 104: EVALUATION OF ABILITY TO WORK

A finding of disability must be based on a realistic evaluation of the individual's capacity to meet the demands of competitive work on a sustained basis. The amendment requires SSA to seek relevant information from medical, vocational, and other sources about capacity to work. A work evaluation is required before a mentally impaired individual can be found not disabled.

SECTION 105: CONSIDERATION GIVEN NONCOMPETITIVE WORK

SSA may not base a conclusion that someone can work solely on employment in a sheltered or noncompetitive work environment. SSA can, however, use insights about the individual's performance and capabilities in those settings in reaching a decision.

SECTION 201: MORATORIUM ON MENTAL IMPAIRMENT REVIEWS

Continuing disability investigations (CDI's) of mentally impaired recipients are stopped until SSA revises the standards and procedures for evaluating mental impairments consistent with current medical and scientific knowledge. The eligibility of initial applicants evaluated under current criteria and the eligibility of those terminated through a CDI since March 1981 must be redetermined once revised standards are issued through new regulations.

SECTION 202: PAYMENT OF BENEFITS DURING APPEAL

Public Law 97-455 provisions relating to continuation of benefits and medicare eligibility through the administrative law judge (ALJ) hearing are made permanent. The amendment also authorizes continuation of benefits and medicare eligibility through the appeals council review when the council has decided to review an ALJ decision favorable to the appellant.

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[3] Interview with Jean Hinckley, General Counsel's Office, SSA.

SECTION 203: PRETERMINATION NOTICE AND RIGHT TO PERSONAL APPEARANCE

The State DDS must give a disabled person detailed notice of any intended decision that is wholly or partly unfavorable and must inform the person that he has 30 days to request a personal interview and provide additional medical or other evidence. After the interview, the State agency will issue a final decision affirming, modifying or reversing its preliminary notice. Appeal of an unfavorable decision will go directly to an ALJ. The reconsideration level of review is eliminated as unnecessary and duplicative.

SECTION 204: CASE DEVELOPMENT AND MEDICAL EVIDENCE

In reviewing eligibility, SSA must consider the complete medical and vocational history, including all evidence in the file from prior evaluations. SSA must also develop a complete medical history of the person being reviewed, covering the preceding 12 months. Every reasonable effort must be made to obtain information from the beneficiary's physician before a consultative examination is ordered.

SECTION 205: ASSISTANCE WITH THE CDI PROCESS

SSA must contact recipients scheduled for a continuing disability investigation (CDI) and determine whether they will need help in complying with instructions for the review. If help is required or if the person asks for assistance, SSA must provide it or refer the person to a local agency or organization which will assist the recipient.

SECTION 206: ACCESSIBILITY AND REIMBURSEMENT REQUIREMENTS FOR HEARINGS

SSA must hold disability hearings at a location and in a building reasonably accessible to the disabled applicant. SSA must also reimburse an applicant who presents evidence of financial need (in advance if necessary) for expenses of obtaining and presenting medical evidence, travel costs, attendants and witnesses.

SECTION 207: QUALIFICATIONS OF DDS MEDICAL PERSONNEL

Decisions on medical eligibility benefits must be made only by appropriately qualified professionals. Determinations of mental impairment can only be made by a psychiatrist or psychologist.

SECTION 208: REGULATORY STANDARDS FOR CONSULTATIVE EXAMINATIONS

SSA must issue detailed regulations setting forth (a) the standards to be used by State agencies and Federal personnel to identify consultative examiners and refer individuals to them for medical examinations; and (b) mechanisms for monitoring the quality of CE referrals and reports.

SECTION 209: PAYMENT FOR CONSULTATIVE EXAMINATIONS

Consultative examiners will be paid for their services at the medicare part B rate for comparable physician services.

SECTION 301: UNIFORM STANDARDS

SSA disability programs are bound by Administrative Procedure Act requirements of public notice and comment prior to publication of a final rule. Moreover, only published rules promulgated pursuant to APA—not informal policies—will apply uniformly at all levels of decision making.

SECTION 302: COMPLIANCE WITH CERTAIN COURT ORDERS

SSA must apply rulings of circuit courts of appeals to all beneficiaries in the circuit or request review of the decision by the Supreme Court. If the Supreme Court does not accept review, circuit court rulings will apply in all States of the circuit until the Supreme Court rules.

SECTION 304: CONTINUED ASSISTANCE FOR POTENTIAL CONCURRENT BENEFICIARIES

SSA must inform all OASDI beneficiaries, who may be eligible, that assistance in applying for supplemental security income is available upon request.

Chairman HEINZ. Mr. Snyder, thank you.

Ladies and gentlemen, you have provided some very, very valuable testimony to the committee, and in one sense I am grateful to Mark Hudson for coming all of the way from Indiana to be here, and in another sense I do not know quite how to address a few questions to him, because he represents all the disability examiners, who, after I listened to your fellow witnesses, either should be hardhearted, incompetent, or too rushed to be able to do a good job.

Mr. HUDSON. Those probably do not belong to our association.

Chairman HEINZ. The first two do not belong, but quite seriously, what Ms. Samuels points out is that examiners are making poor decisions. In the case she described, a person with cardiac and neurological disorders, was sent to a psychiatrist, and from a psychiatrist to an internist, who does not necessarily know much about thoracic surgery or cardiology or neurology, as the case may be.

What can you say? How can you throw some light on this? You look like a sharp fellow. Are you the exception that proves the rule? What is the situation with your fellow examiners?

Mr. HUDSON. It is very tough to know the individual case, but what I can surmise of what might have happened is, first of all, the disability examiners are quite concerned about the harshness of the regulation.

But what could have possibly happened in this particular situation, Senator, would be the fact that all of the other impairments before the mental impairment had been looked at, and it was the professional adjudicator's opinion that the listings of impairments were not met or equaled in this situation.

However, since there was a mental impairment alleged, that was investigated, or more, along the way it could have come up in other medical reports, I am not quite certain.

I see Ms. Samuels shaking her head.

Chairman HEINZ. I think what you said, to a nonexpert, namely myself, is revealing, and that is to say that a neurological problem might be equated with a mental impairment? They are not necessarily the same?

Mr. HUDSON. That is true.

Chairman HEINZ. So in a sense, it is easy to see how somebody not trained in some of these areas could make judgments that are frankly just the wrong ones.

I have a question that none of you exactly touched upon. You said what we should do—and you all virtually unanimously agreed—that we should establish a medical improvement standards and the face-to-face hearing at the reconsideration level does not resolve all our problems with the continuing reviews.

Now, what is the evidentiary hearing going to be like? I would like to just draw that out. What SSA's position is right now, as testified to by Martha McSteen before the Finance Committee a week or so ago, was that they wanted to continue benefits only through the first evidentiary hearing, and not through the ALJ level.

One of you indicated that you could not possibly develop a sufficient evidentiary record by that point. Was that you, Ms. Samuels? Who made that point? Or was it Ms. Naiditch?

Ms. SAMUELS. No; it was not me, because in terms of Zena—I am sorry, in terms of Vera Heiser's case, she definitely had everything—the administrative law judge definitely had every consideration, and that administrative law judge ultimately decided it reflected a disability. So her case was really fully in evidence before the reconsideration termination was issued.

Chairman **Heinz**. Is there any reason to believe that if that did become an evidentiary hearing—and the case of Ms. Heiser would seem to contradict this—that reconsideration would serve as a meaningful decisionmaking point, would SSA reinstate benefits for more people at that point, rather than send them all to the ALJ, where up to 70 percent of them. in some cases, and 75 percent, as Ms. Naiditch mentioned, get reinstated 6 to 15 months later by the ALJ?

Ms. **Samuels**. Yes, I could answer that.

Chairman **Heinz**. Please do.

Ms. **Samuels**. I think, in theory, the reconsideration stage could be a productive exercise. Unfortunately, it is not now, it never has been, and it is not likely to be, and the reason that I say that is that as Social Security has designed the new and not yet instituted face-to-face reconsideration—I hate to call it a hearing, in fact—will be so superficial it is bound to be a farce.

Let me just indicate to you——

Chairman **Heinz**. Could you hold it 1 second?

Ms. **Samuels**. Yes.

Chairman **Heinz**. Now, Mr. Hudson's people are the main actors in the farce.

Mr. Hudson, do you agree with Ms. Samuels?

Ms. **Samuels**. Let me explain why I say that.

Chairman **Heinz**. You can in a minute.

Ms. **Samuels**. OK.

Chairman **Heinz**. You can in 1 minute.

I just want to get Mr. Hudson's opinion on this issue.

Mr. **Hudson**. No.

Chairman **Heinz**. You do not agree?

Mr. **Hudson**. No; I think that the whole problem that has been talked about up here is the level of independence that you see between the examiners versus the administrative law judges in the review of evidence and the determination of facts, and from those facts a conclusion.

What you need to do would be, according to Ms. Samuels, to give the hearing officer the ability to determine the facts from the evidence, and that is, indeed, what the Social Security Administration is going to do in these programs—in these hearings.

The strict adherence to—I hate to say this, with Social Security Administration people here, but my interpretation is that the decisionmaking——

Chairman **Heinz**. Do they put pressure on you, the Social Security people?

Mr. **Hudson**. Well, sure. Our quality is reviewed.

Chairman **Heinz**. As I understand, it is mainly your reinstatements that are reviewed, not your terminations?

Mr. **Hudson**. The terminations are reviewed, quite honestly.

Chairman **Heinz**. Seventy percent of the time?

Mr. **Hudson**. I am not exactly sure of the percentage. I know in Indiana we get more back than we want to, but——

Chairman HEINZ. This is not quite what we were talking about, but do you have any way of knowing which is reviewed more by Social Security, the terminations or the continuances?

Mr. HUDSON. No, I do not, but I do know that in Indiana, my home State, we have more termination benefits returned than we do continuances of benefits. So there obviously has got to be some review.

Chairman HEINZ. You terminate a lot of people, however, I suppose?

Mr. HUDSON. Sure.

Chairman HEINZ. So you could get a sample size, but is it the same using the——

Mr. HUDSON. But it is my understanding that the percentage of terminations has increased.

Chairman HEINZ. Very well. Please continue. You were saying that you thought that the State examining agencies could do a job if they had all of the facts.

Mr. HUDSON. No; not if they had all of the facts, if they had the independence to determine the facts from the evidence, the same way the administrative law judges will, and my interpretation of the evidentiary hearing process is that the hearing officer will, indeed, have that type of independence.

Chairman HEINZ. What you are saying is that you are being told to make certain kinds of decisions, that were you not being told to make them, you would not make?

Mr. HUDSON. That is probably correct.

Chairman HEINZ. Exactly how does that work?

To put it in plain English, you are told to make decisions that you think are wrong, and you go along with it?

Mr. HUDSON. That could be correct, and without a doubt there are situations——

Chairman HEINZ. I do not mean personally, but the system that your people are in, is to make wrong decisions, and you make wrong decisions knowing the system, and what you are saying is that most of the people in the system know that they are wrong decisions?

Mr. HUDSON. Right. Quite a few. OK.

An example would be the stress test on a cardiac case. We have various instructions on what the stress test indicates, and that is adhered to very strongly, but I do not think an administrative law judge has that type of—is bound by such guidelines as we are.

Chairman HEINZ. You say, Mr. Hudson, that you believe the new system being proposed by Mrs. Heckler is going to give the independence to the examiners that they need to make these decisions? Do I understand you correctly?

Mr. HUDSON. Right. The training that I received at McGeorge School of Law in California has given us that type of independence.

Chairman HEINZ. Now, Ms. Samuels, you had some reasons why this was not going to work?

Ms. SAMUELS. Yes; OK.

Chairman HEINZ. I wanted to find out what it was before I found out why it was not going to work.

Ms. SAMUELS. All I can tell you is what Social Security published in the Federal Register by way of proposed regulations in August,

August 15, 1983. They have indicated that they will not change those regulations, even though at the time they were published the expectation was that Federal employees would be doing the face-to-face reconsiderations, not the States.

Now, the States almost exclusively, or uniformly, have decided that they would prefer to handle these, but, nonetheless, the Federal regulation issued by Social Security, Mrs. Heckler says will not be changed.

Second, along with the official regulations that have been proposed, are directives and guidelines that Social Security has issued to effectuate the face-to-face process. Those regulations, directives, and guidelines are really fascinating.

First, there is no uniform agreement, even within the proposed regulations, as to what the reconsideration conference will include, whether or not only medical factors, or both medical and vocational factors will be considered.

Now, if it is only medical factors, then we are talking really about the listing of impairments, which is precisely what they did with Vera Heiser. We are not talking about considering the situation of people who have been in the past determined disabled by reason not only of their medical condition, but as a result of their age and their education, and their past work experience.

So if only medical factors are going to be considered in this reconsideration face-to-face conference, big problems arise as to the parameters of the review.

Second, the authority of the hearing officer—and again I do not like to use the words "hearing officer," as I do not think these really are hearings, but at any rate, the officiators of these face-to-face conferences, they can take evidence, they can listen to testimony and they can make a decision, but they can be reversed by supervisors who are not present during the hearing. That seems totally arbitrary and highly questionable.

Third, the hearing officers are entitled to consult experts, vocational experts, medical experts, without giving any notification to the client, of who is looking at, evaluating or giving opinions on his or her claim, and the client therefore has no right to cross examine, has no right to subpena, has no right, in fact, to challenge any of the evidence, or any of the conclusions drawn by Social Security personnel in evaluating the evidence.

Next the State division of disability determination, which is the agency in every State which evaluates these disability claims, at the first two levels, initially and at reconsideration, will have control of the file. They will prepare the file to go to the hearing officer. They have been directed to limit the evidence only to current disability. In other words, to exclude all evidence relating to the original finding of disability.

That means that a medical improvement standard could not possibly be applied, because none of that old evidence is going to be in the file. The DDS is supposed to also prepare a summary of the evidence for the hearing officer, and that summary, pursuant to Social Security's directive on the subject, is supposed to be incorporated in the hearing officer's decision.

Now, there are some problems with that, because if these summaries are made part of the record, and the hearing officers are under time constraints, which Social Security has very clearly delineated, the hearing officer is very likely never to look at the record itself. That is to say, never to actually review the evidence.

Now, let me tell you about those time frames that Social Security has suggested. The hearing officer is to review the file before the hearing, 20 to 25 minutes. The hearing officer is to hold the hearing 30 to 45 minutes. The hearing officer is to complete the writing of the decision in 20 to 25 minutes. That is a lot of consideration. And the hearing officer is supposed to complete at least four to five hearings, plus decisions, each day, and most decisions are to be made by the day after the hearing.

In addition to all of those very rigid and limited time frames for this face-to-face reconsideration process, because SSA expects a 12-percent no-show for the scheduled conferences, they have directed that there be an overscheduling of these conferences by 12 percent per day.

Now, these are actual directives issued by Social Security. They are not in the regulations, but they are there, and one presumes that they will be there when the States take over this process.

Chairman HENIZ. Let me then ask Mr. Hudson, Mr. Hudson, if Ms. Samuels is correct in what she says, are you still as confident things are going to work out as well?

Mr. HUDSON. I think that Ms. Samuels will be quite surprised when she attends her first hearing. Some of the things she said would not be in existence.

There will be, for example, subpena powers, et cetera.

Chairman HEINZ. Will there be supervisory reversal?

Mr. HUDSON. There will be supervisory review.

Chairman HEINZ. Would that review also include reversal? Would the supervisor have the actual power to reverse, or will the supervisor simply be able to say to you, you had better reverse it? Will you have the independence to say, "no," to the supervisor? How will that work?

Mr. HUDSON. To be quite truthful with you, Senator, I am not aware of the answer.

Chairman HEINZ. All right. I think that has been a very useful exchange to me and the committee, as that will give us a record that will be extremely useful, as we have made it, and we are going to make special note of that.

I want to ask Zena Naiditch some questions.

Ms. Naiditch, what has happened to people thrown off the rolls here in Illinois? How many find employment? How many that have been thrown off the rolls have to go to costly State institutions, public hospitals, homeless shelters, among those that are no longer eligible?

Ms. NAIDITCH. I can tell you, based on our experience, that I am not aware of any that have been able to go out and get jobs.

Chairman HEINZ. Not a single person?

Ms. NAIDITCH. Not that we have directly served or heard about from other advocacy/legal assistance organizations.

Chairman HEINZ. These are people with developmental disabilities?

Ms. NAIDITCH. Right.

Chairman HEINZ. And those constitute about one-third, 27 percent of all of the people who have been thrown off the rolls to date, and you do not know of any of them who have been able to get a job?

Ms. NAIDITCH. Most of the people we see would like to work, but their disability prevents it. They turn to SSI and SSDI as a last resort, sometimes, after unsuccessfully trying a job training program or trying to hold down a job.

Chairman HEINZ. Would that be the less competent, or the more competent, the worst disabled, or the less disabled?

Ms. NAIDITCH. The Protection and Advocacy Board receives requests for assistance from persons with a range of disabilities and whose disabilities vary from mild to severe.

Chairman HEINZ. You get the range, so it is an average group, in other words?

Ms. NAIDITCH. I think that is a fair statement. Our advocates are getting and 80 to 90 percent reversals rate at the ALJ level. Most of our clients have their benefits reinstated. They just are not capable of working. Some of them are participating in workshops, but they are not able to work in a competitive work environment.

Chairman HEINZ. I suppose you are the wrong person to ask, because you get all of those reversals. There are not that many who are being thrown off the rolls. You are saying 20 percent, 10 to 20 percent at most, but of that 10 to 20 percent, how many do go in to more costly settings for care?

Ms. NAIDITCH. Reliable statisitics are not available at this time; however, based on our discussions with State and local agencies, it is clear that persons terminated from the program have few options available to them. We have received calls for assistance from service providers who have clients who are considering nursing home care rather than independent living because they lack the resources necessary to cover basic costs in the community, such as rent, food, and clothing.

Chairman HEINZ. Do any of you have any information on the extent to which when people are cut off the disability rolls they have been unable to find work, they have been told they should work. I am not talking about the ones reinstated, I am talking about the ones who did not make it, either because they did not appeal to the ALJ, or because they took appeals and lost?

And, second, among those that could not find any work, how many of them end up as additional cost to State and local governments, by going on SSI, or going on welfare, which is substantially paid for by the State?

Does anybody have any information on that subject?

Mr. ANTOLIN. First of all, to clarify one point, someone who is cut off of title II benefits, is not going to be put on SSI, since the standards of disability are the same.

Chairman HEINZ. Right.

Mr. ANTOLIN. So their option is, once their benefits have been cut off, if they are a single individual, living alone, as many of our elderly disabled are, to go to the State general assistance program. If they are younger and have children who are under age 18, they may then receive aid to dependent children, AFDC.

Most people we see at the Legal Assistance Foundation of Chicago who ultimately do not win will end up having to go to general assistance. Our agency handles somewhere in excess of 1,000 administrative hearings a year.

Chairman **Heinz**. In Illinois, what proportion of General Assistance is paid by the Illinois taxpayers?

Mr. **Antolin**. It is completely paid by Illinois taxpayers.

Chairman **Heinz**. One hundred percent. So although it pays at a much lower stipend than disability, in most, or I would think in virtually every instance——

Mr. **Antolin**. It pays 45 percent of the SSI rate.

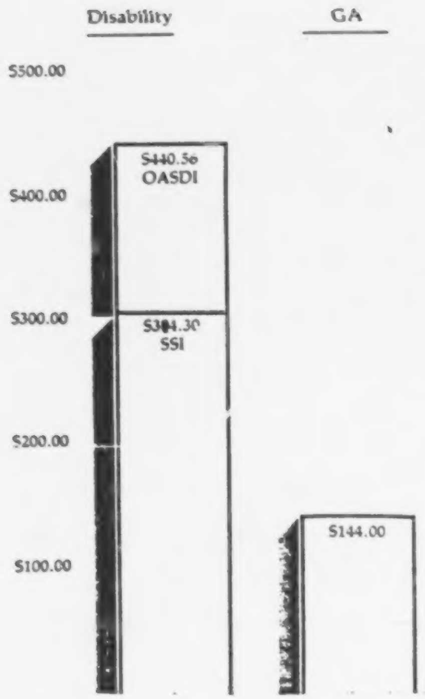
Chairman **Heinz**. Forty-five percent of SSI. The cost is completely shifted to the State in this instance.

Mr. **Antolin**. The cost is also placed upon towns and counties, townships, and counties in the State, for two reasons. One is that our State general assistance program only covers certain townships and counties. There are a lot of nonreceiving townships, who do not receive money from the State government to provide this assistance.

So their benefit levels are even less than $144.

Difference in Benefits

Cash



Medical

Disability	GA
INPATIENT	
comprehensive	$500
OUTPATIENT	
not limited to certain illnesses	limited to: surgery, dialysis, cancer therapy, burn treatment
DRUGS	
substantial	only those necessary to prevent death (*not* to cure illness)
MEDICAL SUPPLIES	
substantial	limited to those essential: —for hospital discharge —to prevent institutionalization or medical emergency —to prevent death

Second, the medical coverage is so low, because the State is in its own fiscal trauma, that people do not get ongoing medical services.

What is covered are emergency services, that hospitals have to accept individuals for, and really nothing else. As a result, a county hospital, such as Cook County Hospital, which is funded by the county, and has to provide services to whomever walks in, is experiencing something on the order of a 300-percent increase in the last year of people demanding their services, who cannot get those services under the GA medical grant at other hospitals.

Chairman HEINZ. Thank you very much, Mr. Antolin.

Mr. Hudson, you made a very interesting suggestion with respect to what I might call, grandfathering, namely, that if someone had been on the rolls for 5 years, at 55, or if they had been on the roles 10 years at age 50, then they should be considered functionally disabled.

Mr. HUDSON. That is correct.

Chairman HEINZ. Would you, under the new proposal by SSA and HHS, be able to follow such a standard, or would it take a specific act, by either Congress, or regulation, or POMS, for you to do it?

Mr. HUDSON. It would take specific action.

Chairman HEINZ. By regulation? By POMS?

Mr. HUDSON. Yes.

Chairman HEINZ. Would it be done by POMS, or could it be done by regulation?

Mr. HUDSON. It would have to be done by regulation, I believe. This was originally a part of the Pickle bill, when it was first introduced into Congress.

Chairman HEINZ. That brings me to what I think is going to be my last question—it may be my last question.

Ms. Naiditch, you made another interesting suggestion about a national task panel. I gather that task panel was meant to operate, in a sense, independent of anything we might do in Congress, as I understood your suggestion. That is, Congress would not have to wait for a national task panel to make recommendations, or would it, just so I am clear on that point?

Ms. NAIDITCH. No. What we were suggesting is that since HHS has agreed that there is a need to review and reform some of its policies and practices that it establish a panel to provide advise and technical assistance. The panel should include representation from the National Governor's Association, advocacy and legal assistance organizations, and experts in the field of developmental disabilities, mental health and medical experts.

Chairman HEINZ. That is what I thought you meant, and that brings me to the question I was really driving at, which is, in the Pickle bill, as I recollect it, it requires that new rules be established under the Administrative Procedures Act, which is a more formal review process open to public comment.

Are you suggesting, because I want it just to be clear on the record, that a national task panel help HHS and SSA write POMS which are written frequently, and updated frequently, as a valid substitute for putting all POMS under the Administrative Procedures Act?

Ms. NAIDITCH. No, the advisory committee could provide input on a regular basis on a variety of issues. It could assist in developing the proposed policies which go through the Administrative Procedures Act. It also could evaluate the impact of the new policies on the program's beneficiaries.

Chairman HEINZ. It would seem to me the ideas are mutually exclusive. You do one or you do the other. If you had an APA procedure with all the hearings and public input, it would seem to me relatively superfluous to involve a task panel such as you have described, in the POMS setting.

Ms. NAIDITCH. My concern concern is that Social Security is constantly issuing new directives, policies, and procedures with little input from organizations which represent the interests of disabled persons. Use of an advisory panel should improve the quality of SSA's proposed policy changes. I am not sure that the two proposals—an advisory panel and requiring that POMS comply with the Administrative Procedures Act—need to be mutually exclusive.

Chairman HEINZ. Does anybody else have a comment on this issue?

Mr. ANTOLIN. I have.

Chairman HEINZ. Yes, please, Mr. Antolin.

Mr. ANTOLIN. There are three levels of regulations in the SSA. There is the POMS, there is SSR's, and then the regulations that are promulgated under the APA. The SSR's are rulings that are binding on all components, all decisionmakers, the State agencies, the ALJ's, and the appeals council. So it rises to the level of a regulation, it just has not been promulgated pursuant to APA.

What is insidious about the present practice is that the POMS are being elevated to the level of a regulation by SSR's, so that you may have a regulation published in the Code of Federal Regulations, which does not appear to be—which has not been changed, and in fact, its meaning has changed to a much more restrictive standard, because what the administration has done is taken its POMS and made it an SSR.

Chairman HEINZ. What is the difference between a regulation and an SSR?

Ms. SAMUELS. Well, a regulation is published, and you have an opportunity to comment, and they——

Chairman HEINZ. What does the term "SSR" stand for?

Ms. SAMUELS. SSR stands for social security rulings, and they are the product of the Social Security Administration, independently, privately, without any formal publication, interpreting or creating new rules and regulations.

Chairman HEINZ. Anybody who has followed the Federal income tax system knows what a ruling is, and I think we all now understand what that is.

Thank you.

I guess I have got one more question for Ms. Naiditch, which is this.

You mentioned that Mrs. Heckler, Secretary Heckler, did not impose a moratorium on those beneficiaries who were partially developmentally disabled and partially physically disabled.

How bad a mistake is that? Do we have a lot of people falling through that particular crack? How big is the crack?

Ms. Naiditch. I understand it is fairly large. Again, I do not have the numbers.

Chairman Heinz. Lastly, for you, returning to the question of developmentally disabled who had been cut off, we hear a lot of stories of street people. We hear some people saying that they want to be homeless, which does not make a lot of sense to me, unless the person is out of—literally out of their mind, or has an extraordinary low IQ, or their mind does not function very well or logically.

Are some of the people we see on the street today the developmentally disabled who have been cut off the disability program?

Ms. Naiditch. I would guess that some of those people were at one point.

Chairman Heinz. A small fraction, a substantial fraction?

Ms. Naiditch. There are not that many options available to a DD person who has been terminated from the program. I suspect some who try on their own to secure alternative resources from State and local government never link up.

Ms. Samuels. It is extremely hard to say, because those are the people who because of their problems are the least likely to be able to find help. So they are not the ones that we see.

Chairman Heinz. I understand that.

My very last question, I guess, is for Tim Snyder.

Mr. Snyder, can you, from your experience, generalize at all, or for the record, provide us with examples of cases you have encountered, in which terminated beneficiaries cannot work, and there is no hope for their rehabilitation, and can you testify at all, or generalize at all about that?

Mr. Snyder. I have not personally encountered that. I also have a history of being a rehabilitation counselor, and have dealt with people who have been on social security disability insurance, in terms of working with them as a vocational counselor, and have had individuals in the past who have been cut off from benefits, and had to go back through the appeal, at which time we were not saying they could work, they were just not readily trained to be ready to work. They were in the midst of a training program, or something, and were cut off at that point in time.

Chairman Heinz. Senator Percy, do you have any questions you would like to ask the panel?

Senator Percy. Mark Hudson has an unusual ability to help us in a couple of areas. I understand that you were involved, and are currently involved, in the implementation of hearings at the reconsideration level that just began this year.

Could you provide the committee with some sense of what these hearings involve, and how they will improve the review process?

Mr. Hudson. Certainly, thank you.

Yes; I am quite enthused about the evidentiary hearing process. As I have stated in my testimony, I think it is a right direction that the Congress has initiated, and that social security is implementing on the national scene.

I am impressed with the training that is being received. It is at the McGeorge School of Law in Sacramento, Calif. Every hearing officer will go to a 2-week training program.

I think it is a humane manner in which to treat the claimants who have had their benefits ceased. My concern, as I have stated in my testimony, is that I wish that could be extended to all levels of adjudication.

Senator **Percy**. Finally, the Social Security Administration opposes instituting a face-to-face hearing at the initial decision level, and doing away with the reconsideration stage altogether, as some in Congress have proposed.

What would be your own attitude on this issue?

Mr. **Hudson**. The reconsideration rate has such a small reversal rate that I think I would agree with the Congress.

Senator **Percy**. I would now like to turn to the representative from the university within a mile of my house, Barbara Samuels. I understand you have represented a very large number of disability beneficiaries who have been affected by the continuing eligibility reviews.

Can you describe to us how a medical improvement standard would concretely affect cases that you have actually handled?

Ms. **Samuels**. Sure.

At this point there is no attempt whatever to apply or to even question whether or not the condition of the claimant has changed since the original determination of disability, and what that means in a practical sense is that very little effort is made to complete the record.

Now, for a long time, Social Security had—since the institution of the program, as I understand it, has taken the initiative in trying to obtain records so as to help clients document their case.

But in the termination situation, very little effort is being made to make sure that the record is complete, or to even incorporate the old record with the additional documents that may be considered on review for termination.

What that means is that Social Security is looking at a more rigid evaluation standard, because the regulations have not changed, and the statutory definition of disability has not at all changed. It is solely what a person's condition is as of the day of review, and without any reference to the course of medical history, the complications of a condition, or even a sense and understanding of what the condition may involve as, for instance, Ms. Heiser's condition.

Additionally, I had a client with tuberculosis of the spine, who was told on reconsideration, after she had been on disability for approximately 4 years, that her arthritis was better. And that is not unusual. The wrong standards are being applied. The wrong evaluations are being done. The wrong consultative examinations are being obtained and paid for with Federal money, examinations that do not evaluate what is wrong with the claimant, or evaluate it thoroughly and appropriately.

Mr. **Antolin**. If I may, Senator, I would like to address a second aspect of why medical improvement is so important.

As lead counsel in the class action suit that has been filed in the State, one of the underlying principles of medical improvement is fundamental fairness. Once someone has been placed on the rolls, has received benefits, has been determined to be disabled, if you do not use the standard of medical improvement, then that person is going to be subjected to a different evaluation solely because we have a different decisionmaker looking at the evidence.

In many cases they do not look at the correct evidence, as Ms. Samuels pointed out, and even in the cases when they do look at a current evaluation of the correct impairment, two different people are likely to come out differently on the same case. And that is one reason why medical improvement should be the standard; because medical improvement means there is a presumption the person has met the requirements, and it is now the agency's obligation to show, in fact, that it was clear error, that medically, scientifically, objectively, the condition has improved to the point where they can now return to the labor force.

Senator PERCY. Mr. Antolin, while you are addressing yourself to this, could you think back in your experience. What are the most likely cases to be terminated by the Social Security Administration? Could you just give an example of one or two that occur to you?

Mr. ANTOLIN. Well, for the first year and a half of the review process, the terminations focused, to a great extent, on mental impairments. If there was a mental impairment, terminations were commonplace, because they are the most difficult kinds of impairments to assess.

What we see now in increasing frequency are terminations on the long-term disabilities, such as Mr. Vance, which do not require monthly treatment, a condition that is lifelong, that is not going to get any better. Those terminations are very common, and also terminations that involve arthritis or disc problems or heart conditions.

Senator PERCY. Thank you very much, indeed.

Mr. Snyder, your organization does a great deal to help people who are disabled adjust to so-called normal community life.

Can you tell me if any of the people your organization deals with have, to your knowledge, had experiences similar to those our first panel told of?

Mr. SNYDER. I surveyed the individual staff people who work for us with respect to identifying selective cases, and I think in our situation the majority of our clients are so severely disabled, and their disabilities are quite visual, in terms of using assisting devices to get around, by ambulation, or using wheelchairs or such, that we have not come upon many cases.

In fact, we were not able to isolate one particular case that we have come upon that had been reviewed and had benefits terminated.

Senator PERCY. Fine.

Thank you very much.

I also want to tell our chairman that Access Living does a tremendous amount to prevent people who do not want to be institutionalized from being institutionalized. As I have traveled in Illinois, as I did yesterday, going across the top of the State, starting here and ending up finally on the Mississippi River, in Galena——

Chairman HEINZ. On the Mississippi.

Senator PERCY. Not in it, but on it.

I went into the senior citizen centers that have been built there—many with revenue sharing funds—and I found that was one of the principal things they were aiming at. People do not want to be institutionalized. They wanted to be kept in their own homes.

Meals-on-Wheels, lunch programs, and all kinds of care services that are all offered to the home, save this Government an infinite amount of money. It also provides a great deal more happiness for the people who just want to be in their own home, if they can possibly make it on their own ability, with some community help.

Finally, to Zena Naiditch, how are the developmentally disabled affected particularly by the continuing eligibility reviews?

Ms. Naiditch. Developmentally disabled persons have been included in the review process. The board uses the Federal definition of DD, which includes some of the chronically mentally ill, the mentally retarded, persons with epilepsy, cerebral palsy, and other conditions where the onset of the disability is prior to the age of 22 and which result in basic functional limitations. Yes, the mentally ill, mentally retarded and other persons with DD have been hit hard by the review process.

Senator Percy. What happens if the developmentally disabled are removed from the rolls? What services are available to assist them in finding work, or maintaining their income?

Ms. Naiditch. Many of the people that we have dealt with end up turning either to State or local welfare programs, residential programs in State institutions or nursing homes.

Our concern is not just the shift in financial responsibility from the Federal Government to already overburdened State and local government programs. Movement of an individual from SSI or SSDI to a State welfare program means a much lower standard of living. Someone on SSI gets about $314 a month and medicaid. If he is forced to go onto the State assistance program, he'll probably receive $144, and very limited medical coverage, for example, general assistance recipients have a maximum of $500 per year hospitalization coverage.

Others have come to us who have been living independently in the home, participating in day programs, who feel that without their income they may be forced back into more institutional settings where medicaid coverage is available.

Chairman Heinz. I want to thank you all. You have been a marvelous panel of witnesses. You have helped us to put a great deal of important information on the record. You have answered innumerable questions, both for Senator Percy and myself.

So I thank you very much on behalf of the committee, and we thank both of you who have come from out of State, from Ohio, from Indiana, you have taken time out of what is obviously a busy day in Illinois, for the contribution you have made to us.

Thank you very much.

Our third panel consists of Jess McDonald, who is the assistant to the Governor for Human Services, and he is accompanied by Robert Granzeier, who is director of the Illinois Department of Rehabilitation Services, and Phil Bradley, administrator of the Illinois Bureau for Disability Adjudicative Services.

Gentlemen, thank you for bearing with us. We ran a little longer and slower than we had originally anticipated, and if you have any written testimony, we will put it in the record, as if given, in full.

We are pleased to have you here.

Mr. McDonald, you are in capital letters here. Are you the ranking member of this group?

STATEMENT OF JESS McDONALD, SPRINGFIELD, ILL., ASSISTANT TO THE GOVERNOR FOR HUMAN SERVICES

Mr. McDonald. Director Granzeier is the ranking member. I represent Governor Thompson, and I appreciate having the opportunity to spend the afternoon here. It has been very instructive, indeed.

I serve as the Governor's assistant for human services. I want to stress that the Governor regrets that be could not attend. He was previously committed out of State this afternoon.

I want to—I will be very brief—I want to inform you as to what steps we have taken in this State, in response to Secretary Heckler's January 24 request for a plan to resume processing the continuing disability review cessations.

We have indicated to the Secretary that we believe, first that we are not properly classified, and that we ought to be classified with those States under litigation, under pending litigation, based on the fact that an action has been filed in our district court in Alton, *Young* v. *Heckler,* which is a class action, and is involving medical improvement, and as such, we have indicated to the Secretary we do not believe it would be appropriate for us to resume full processing of disability cessations.

The Governor has stated that the moratorium that he has placed will remain in place until steps to solve the problems in this program are taken. He supports the position of the National Governors Association, and believes that congressional action is vital to insuring an equitable and consistent national program.

In addition, we will begin here in Illinois the implementation of a number of program improvements designed to reinforce the rights of the disabled, and Bob Granzeier is here to explain some of these actions.

I might preface that by saying that internal advocacy, which is what we are proposing, is a risky business. No one ever believes that you are serious, and that it is an attempt to cover everything up.

I have been reminded by the Guardianship and Advocacy Commission, who has sued us in the past, and by the Protection Advocacy Board, who probably will sue us in the future, that they are working with us, and have committed to work with us in the future, in designing our advocacy operations within the Bureau of Disability Adjudicative Services.

The Governor is committed to the improvement of the Illinois program, and I am sorry that he did not have the opportunity to have the benefit of the hearing today, I think he would have been impressed, and impressed with the urgency that we take action immediately.

Chairman Heinz. Mr. McDonald, thank you.

I know your Governor well. He does an excellent job for the State of Illinois when he comes to Washington, D.C. I have had the opportunity to work with him on the problems of unemployment compensation.

Pennsylvania and Illinois unfortunately share the same problems with respect to the solvency of the State unemployment compensation trust fund.

As a member of the Finance Committee, I may tell you he has represented your State ably and well, and as a result, we were able to write something that was very useful to the State of Illinois, as well as to many States that had solvency problems.

Mr. Granzeier.

STATEMENT OF ROBERT W. GRANZEIER, SPRINGFIELD, ILL., DIRECTOR, DEPARTMENT OF REHABILITATION SERVICES, STATE OF ILLINOIS

Mr. **Granzeier**. Thank you very much, Senator.

I, too, like Jess McDonald, was pleased to be here this afternoon to hear some of the testimony, and some of the recommendations made by the previous groups.

I was not pleased to hear some of the stories that were told by the individuals, and I am equally as distressed as I fear you are regarding those situations.

As has been said on the record, I am director of the Illinois Department of Rehabilitation Services, and a major component of that department is the Bureau for Disability Adjudicative Services.

I am certainly aware, as well as my staff, and equally concerned regarding the numbers of disabled individuals who have had their benefits ceased as a result of the social security regulations.

As director of the department, I am putting into place a number of measures that hopefully will improve our process, in addition to what we hope will take place at the Washington level, and I will recite some of those.

As Mr. McDonald has already said, we intend to continue to work closely with the Guardianship and Advocacy Commission and the Protective Advocacy Board, which we have in the past, and will continue to do in the future.

I plan to, as immediately as possible, establish an advisory council of experts and advocates that will review State administration of the program, and make recommendations to my department and the Bureau of Disability Adjudicative Services on ways to improve, to develop an advocacy ombudsman system in the bureau to help applicants better understand the process.

We have had, within the department, a great deal of experience with the client consumer advisory project, which has been very successful for us in Illinois. We intend to do the same thing with the Bureau for Disability Adjudicative Services, and to establish, when the moratorium is lifted, a safeguard system that will double check all cut-off decisions and denials and original applications; to improve applicant medical files, to increase fees for necessary tests, and to improve communications with the medical community.

We have had a problem here with some of the fees we have been able to pay. We intend to improve that. We intend to again increase the bureau's work with the advocacy groups, and other organizations concerned with helping the disabled.

I might say also, Senator, that the testimony from Access Living—and the director of Access Living is here also—just for the record, the funding of Access Living is recommended by my department, and is pretty much passed through my department, so we are equally as concerned with that situation they are faced with, in trying to help the citizens go to them.

We intend to recruit Hispanic adjudicators in the bureau to help Spanish-speaking claimants and physicians.

So those are some of the things we can do, and will do, within Illinois to improve our process.

Thank you.

Chairman Heinz. Very well, Mr. Granzeier. Thank you very much.

Mr. Phil Bradley, do you have anything you want to add to what has been said?

STATEMENT OF PHILIP BRADLEY, SPRINGFIELD, ILL., ADMINISTRATOR, BUREAU OF DISABILITY ADJUDICATIVE SERVICES, STATE OF ILLINOIS

Mr. Bradley. Senator, I appreciate the opportunity to be here. I have been here primarily to listen, and to let people know that those of us "on the line" who are running the programs are, indeed, concerned, and to be here should you have any questions for us. Our basic message is that it is a difficult program for States to administer, and that significant reform has to come from the level of Washington, D.C.

Chairman Heinz. I am going to ask, with unanimous consent, that the release detailing the things that you have talked about today be placed in the record at an appropriate point, and I am also going to ask that the testimony from the Illinois Alliance for the Mentally Ill, submitted by Laura Guilfoyle be placed in our record at the appropriate point,[1] and without objection, both of those are ordered.

[Letter and other material follow:]

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[1] See appendix.

State of Illinois
Department of Rehabilitation Services
Robert W. Granzeier
Director

AUG. 26th 1818

623 E. Adams, P.O. Box 1587
Springfield, IL 62705
(217) 782-2093

160 N. LaSalle, Room 1029
Chicago, IL 60601
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February 16, 1984

Senator John Heinz and
Senator Charles Percy
United States Senate
Washington, D.C. 20510

Dear Senators Heinz and Percy:

I want to apprise you of the current status of the Illinois DDS, which as the Bureau of Disability Adjudication Services, is under my direction.

Governor Thompson has just responded to Secretary Margaret Heckler's request that we begin processing continuing disability review cessations in Illinois. Since a class action lawsuit has been filed in Federal Court in Alton, we believe that Illinois is in the category of states with pending litigation. We do not believe that we should consider resuming processing if indeed we are in that category. Therefore, the Governor has asked Secretary Heckler to examine our status. A copy of the Governor's letter is attached.

The Governor has carefully reviewed the operation of the disability program in our state and has directed that we take some actions at the state level to improve the program's functioning. We believe these actions are prudent, within SSA guidelines, and that they will protect the rights of disabled people in Illinois.

The key actions which the Governor has asked us to take are: 1) Establishing an Advisory Council to provide an ongoing review of the DDS' operation, and 2) Developing an advocacy/ombudsman function within the Bureau so that claimants will be able to contact individuals trained in helping them work through the process.

In addition, we intend to improve the quality of the medical file of applicants through increasing rates in our Departmental Medical Fee Plan. This should enhance our ability to get complete medical data and to receive reports from treating physicians. We also plan to do a 100%

Quality Assurance review of continuing disability review cessations when we again process CDR's. Other activities will be directed toward enhancing public awareness and understanding of the disability process. A press release from Governor Thompson describing the actions which he has directed us to take is attached.

I appreciate your interest in the disability program. I and my staff stand ready to assist in improving the operation through legislation, administrative directives or state initiatives.

Sincerely,

Robert Granzeier
Director

Attachments

STATE OF ILLINOIS
OFFICE OF THE GOVERNOR
CHICAGO 60601

JAMES R. THOMPSON
GOVERNOR

February 15, 1984

The Honorable Margaret Heckler
Secretary
Department of Health and Human Services
Washington, D.C.

Dear Secretary Heckler:

Illinois appreciates your willingness to continue discussions among the states in order to bring about equity and consistency in the disability program. Further, we recognize our responsibilities under the terms of our working relationship in the administration of the social security disability determination program. We will continue to work with you in planning for the initiation of face-to-face evidentiary hearings. We stand ready to implement these hearings as soon as we can again begin processing since we believe they will provide an added safeguard for the rights of disabled citizens in Illinois.

You have asked that I describe Illinois' plans for resuming full processing of disability cessations.

A class action suit has been filed in the Federal court in Alton, Illinois. That suit seeks review of all Illinois Continuing Disability Review cessations since March of 1981 and asks that a medical improvement standard be applied. I am requesting that Illinois be properly classified as a state with pending litigation along with a number of other states. In these states, I understand that full processing is not being resumed pending the outcome of litigation. Thus, it would also not be appropriate for Illinois to resume processing cessations.

I commend your efforts with Congress to facilitate passage of disability reform legislation as soon as possible. It is vital for the disabled people of Illinois that this program be improved and that it be consistent from state to state. I have urged the Illinois Congressional delegation to work with you toward achieving needed program changes.

I look forward to your favorable determination on our request to be included in the group of states which have pending litigation.

Sincerely,

James R. Thompson
GOVERNOR

JRT:cs

NEWS From the office of THE GOVERNOR

FOR IMMEDIATE RELEASE 217-782-7355

SPRINGFIELD, Ill., February 16--Governor James R. Thompson announced Thursday a series of reforms in the state's administration of the federal supplemental Social Security program designed to further protect the rights of the disabled in Illinois while maintaining a moratorium he imposed in December that prevents the cutoff of aid to the handicapped.

The Governor, in replying to a request from U.S. Department of Health and Human Services Secretary Margaret Heckler for Illinois' cutoff plans, said that a lawsuit filed in Federal court in Alton seeking review of benefit cutoffs since March 1981 means the state should be considered as one with "pending litigation."

"I am requesting that Illinois be properly classified as a state with pending litigation," he said in a letter to Secretary Heckler. "As such, it would not be appropriate for Illinois to resume processing cessations.

"In any event," Thompson indicated, "I cannot agree to the lifting of a moratorium until the 'face-to-face' hearing process, so vital to the interests of the disabled, is in place."

Thompson's action Thursday came about two months after he imposed a moratorium on benefit cutoffs, a move prompted by confusion between federal and state officials concerning the eligibility of benefit recipients. With that action, the Governor protected Illinois residents who could have lost their benefits.

That moratorium, the Governor said, will remain in place until steps to solve the problem are taken. He said that one solution is in legislation stalled in Congress and Thompson called on Heckler to work to pass that measure "as soon as possible."

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"It is vital for the disabled people of Illinois that this program be improved and that it be consistent from state to state," he said. "I will urge the Illinois Congressional Delegation to work with you toward achieving needed program changes."

Thompson said that in addition to protecting current recipients with the moratorium, Illinois will take additional steps aimed at reinforcing the rights of the handicapped and improving state administration of the program.

They include:

*Establishing an advisory council of experts and advocates that will review state administration of the program and make recommendations to the state Department of Rehabilitation Services (DORS) and the Bureau of Disability Adjudication Services on ways to improve it.

*Developing an advocacy/ombudsman system in the Bureau to help applicants better understand the process.

*Establishing, when the moratorium is lifted, a safeguard system that will double check all cutoff decisions and improve quality assurance reviews and denials of original applications.

*Improving applicant's medical files through increased fees for necessary tests and improved communication with the medical community.

*Increasing the Bureau's work with advocacy groups and other organizations concerned with helping the disabled.

*Recruiting Hispanic adjudicators in the Bureau to help Spanish-speaking claimants and physicians.

In addition, handbooks and fact sheets explaining the application process will be developed. Articles for the Illinois State Medical Society Journal will be prepared on a regular basis, and a training program to improve work between state agencies will be created.

In other areas, Bureau staff members will make periodic visits to Social Security district offices and a special training program that improves DORS counselors' knowledge of changes in the review process will be implemented.

The disability program is run by DORS in Illinois, uses federal funds and follows federal guidelines. Before Thompson ordered the moratorium on December 21, however, federal officials have overruled state officials on the eligibility of applicants and claimants, creating confusion in Illinois and other states.

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Chairman HEINZ. Gentlemen, I really do not envy the situation you are in. I think you are trying to cope with an impossible situation, where you have been put between the Devil and the deep blue sea. I do not wish to torment you in this hour of trial, because it is not a torment you deserve, but I have to go on to ask you some questions about the situation. Through no fault of your own, SSA is asking you, as I think was accurately described by Mr. Hudson, to make the wrong decision, and you are being told to go along with it, even though you know it is wrong.

Now, the State of Illinois has commendably said they just cannot do that, and you have implemented a moratorium because you clearly felt that what was was happening was not justifiable, and that moratorium which was ordered by Governor Thompson last December is, as of today, in effect. As I understand from what Mr. McDonald has said, the Governor has sent a plea for clemency to HHS, saying, "I know you are lifting the moratorium, but in effect we do not want to lift it, please tell us we do not have to."

Mr. MCDONALD. Yes.

Chairman HEINZ. Now, the situation in Illinois, as I understand it, is you are still conducting reviews, but no one is being informed that they are to have their benefits cut off. I would think if the moratorium is lifted there is going to be an absolute avalanche of notices to people, saying they have been cut off.

Is that a reasonably accurate description of the situation right now, Mr. Bradley? Have I misstated it? It was not my intention to misstate it, but I just want to know how bad it is.

Mr. BRADLEY. We stopped issuing notices to those whose benefits would be terminated in December. We have processed several cases, which appear to be cases in which benefits would continue, and if they are, we have proceeded with those cases.

It is my understanding that Social Security is not now sending us the bulk of the CDI cases, because we are not processing them.

Chairman HEINZ. Let me ask you this, in *Mental Health Association of Minnesota* v. *Schweiker*, it was found that SSA instituted an arbitrary and capricious policy against those with mental illness, that that policy was enforced through subregulatory means, including internal memoranda, regional and national returns, and reviews.

Are there any other instances of SSA enforcing illegal or unfair review processes here in Illinois through such methods, and did such pressure contribute to your decision to impose a moratorium?

Mr. BRADLEY. I think that is the judgment of the Federal Court to make, as to whether we are enforcing illegal standards.

Chairman HEINZ. Well, I am not asking you as to whether you thought they were illegal.

Mr. BRADLEY. I thought that was what you asked.

Chairman HEINZ. I am just asking you whether there was pressure that you felt to do things that you did not want to do, that you thought were wrong, and whether that was a reason for the moratorium.

Mr. BRADLEY. I think there were two main reasons for the moratorium. One was the end of the benefits payment continuation provisions in December, and that is significant because of the high overturn rate of our decisions at the ALJ level.

We were placed in the position of telling people, "Your benefits are cut off, and there is no safety net for you," and, frankly, I think the Governor thought that was wrong.

But beyond that is the entire question of the propriety of some of the regulations, and the legal status of some of the regulations, which we cannot make a judgment on, but which I think make us uncomfortable. I think the Governor is on record as having voted for the proposals which the National Governors Association endorsed, and would look to that as guidance as to what ought to be done to improve the program.

Chairman HEINZ. I realize you can only speculate about this, because the condition in my question is hypothetical, but had the Congress found a way to continue benefits through ALJ for the rest of this year, do you suppose the Governor would have implemented the moratorium anyway, or, alternatively, would you have recommended that he impose such a moratorium, in any event?

Mr. BRADLEY. I cannot presume to tell you what the Governor thinks.

Chairman HEINZ. Then maybe Mr. Granzeier is the best one to answer.

Mr. GRANZEIER. I would think that another factor was the possibility that the class action suits might be successful in the State, and the Governor's concern that people who are reviewed and cut off might be re-reviewed, and that places us in a difficult situation.

So I think it is fair to say now as things have transpired, benefit payments are part of the picture, but the entire question of the class action suit which is pending enters his consideration at this point.

Chairman HEINZ. Mr. Bradley or Mr. Granzeier, I do not wish to put words in your mouth, but in my observation, it seems to me you are going to an extraordinary extent to avoid saying that the bad decisions, some of the examples of which you saw before your eyes today, played a substantial part in anybody's decision here to impose a moratorium.

Now, I do not want you to take the wrong connotation away here, but let me just put it in the affirmative sense. Did the Governor of Illinois, or any of you, recommend the imposition of the moratorium here in Illinois because you thought this system was producing judgments about disabled people that were wrong?

Mr. BRADLEY. I think it is fair to say that the Governor has heard from significant numbers of people who feel that the decisions are sometimes wrong.

Chairman HEINZ. Now, as a matter of record——

Mr. BRADLEY. I do not know what the Governor thinks.

Chairman HEINZ. As a matter of record—and I should really ask Mr. McDonald—has the Governor indicated, as a matter of record—and I am not asking you to read his mind—that the State's position is that there are some really serious problems caused by this system that result in harm being done to the beneficiaries, harm that is done wrongfully?

Mr. McDONALD. Phil was doing a good job. I will let him keep going.

Chairman HEINZ. I noticed you slid your chair further back.

Mr. McDONALD. I do not feel the least bit uncomfortable saying that I think that the Governor does not know, and I do not know all of the complexities of the processing problems, but there is a good guts sense there is something wrong, when you have as many lawsuits, when you have as many complaints, and when you have—interestingly enough, we get zero letters in the Governor's office about this program. They must be going straight to Washington, or someplace else, but we do not get many complaints about the program. It probably would have helped if we had gotten complaints in our office sooner.

But I think the Governor just had a good guts sense from listening to the problems, being aware of discussions with other Governors, that this problem begged for some type of resolution, and that there was, on the face of it, harm being caused to Illinois' citizens, that we just had to take some action, and we would do whatever we could to sort out the problems that we could sort out in Illinois, and that we would urge for some sort of solution at the Federal level.

Chairman HEINZ. There has been discussion about the announced administrative initiatives of SSA.

From the point of view of the State, do you think that what SSA is proposing is going to solve the problems that you are encountering, and what do you think of the system, in your best estimate?

Mr. BRADLEY. Senator, let me say that we spend $26 million of SSA's money every year. Let me say we are uncomfortable not administering the program they way they say it should be administered.

However, I think it is fair to say that our people see significant problems in the CDR process. The people who have spoken before told you much more eloquently than we can what those problems are, and how they can be addressed by you.

The question of medical improvement is a major question. It is my understanding that was at one time part of the program. The oldtimers in my shop tell me that that would improve the process considerably.

That is not the Governor's position, but my position is that some of the things in the Pickle bill, for instance, are essential to making the process work uniformally nationally.

You have States now who will not do it. You have a serious problem right there. It seems to me that somehow that must be solved on a national level.

Chairman HEINZ. Would one of you do me the favor of stating briefly, for our record, what the National Governors Association's position is on the medical improvement standard? Are they for it?

Mr. GRANZEIER. Yes, indeed.

Mr. McDONALD. They are for it.

Mr. BRADLEY. They are for it.

Chairman HEINZ. And the Governor—you said a moment ago that the Governor is for the National Governors Association's position?

Mr. McDONALD. Yes.

Chairman HEINZ. Therefore, I think you are on firm ground, Mr. Bradley. You do not have to have any hesitation about being for a medical improvement standard.

Mr. **Bradley**. No, I do not, Senator, but I do not think those policy decisions should come from my level.

Chairman **Heinz**. They did not.

Mr. **Bradley**. I think that we need it. I think we need benefit continuation.

Chairman **Heinz**. I thought that would make it easier for you to say so.

Mr. **Bradley**. Let me back up to what Ms. Naiditch said. I think that the most essential solution at this point is a continuation of Secretary Heckler's moratorium, until some of these problems are solved.

Chairman **Heinz**. Gentlemen, do you have anything you want to add?

Mr. **Granzeier**. One thing, if I may, sir.

I take some exception, not total—well, yes, some exception to the face-to-face evidentiary hearings. We felt, and I feel, in Illinois, very comfortable having my staff conduct those hearings, and I agree the process may need change somewhat, but I felt much more—but I am much more comfortable having my staff being involved in those hearings, and I think we could have, and will do a much better job than having Federal people come in and look at these cases on a face-to-face basis.

I think that is also a positive step, to do the face to face.

Mr. **McDonald**. I will take my turn.

After hearing some of the testimony today, I have serious reservations—and having had an opportunity to talk with Chris Lavern from the Guardianship and Advocacy Commission, I have serious reservations about face-to-face after initial denial. I think there is a lot of work that has to be done to assure that individuals will be treated fairly in the system, and the Governor cannot lose sight of the need for a fair and equitable system within the State.

Chairman **Heinz**. Just so I understand Mr. Granzeier's point of view, do you or do you not believe that the evidentiary hearing can be at face-to-face reconsideration?

Mr. **Granzeier**. Yes.

Chairman **Heinz**. You believe that that will work?

Mr. **Granzeier**. I think it will, yes.

Chairman **Heinz**. And you believe that there can be the independence to have those decisions be made independently?

Mr. **Granzeier**. Yes.

Chairman **Heinz**. Do you think that benefits should be continued beyond that stage?

Mr. **Granzeier**. Yes. If it has to go to the ALJ, yes, absolutely.

Chairman **Heinz**. Very well.

Gentlemen, we thank you. We appreciate your patience and your excellent testimony, and we, the committee, ask that you convey our thanks to the Governor of Illinois, Jim Thompson, for making you available. We appreciate it very much.

Senator **Percy**. I want to thank you very much, indeed. Mr. Chairman, if I could just add a personal note. I have been deeply impressed with the devotion that you have had to this field and the expertise that you have developed in it. I have been in it 34 years now, and each year I get more interested in the aging, just as I developed an increasing respect for the seniority system, the more I got of it.

I would also like to say, because I have not had a chance to say so in Illinois and I want to say it in Pennsylvania, that when I could no longer continue as chairman of the Alliance To Save Energy, an organization designed to bring down our—designed to lessen our dependence upon outside energy, find all sorts of ways to provide for ourselves better and save money through saving energy—your chairmanship of the Alliance To Save Energy has been just absolutely outstanding. I am deeply, deeply grateful, as everyone is who is involved in that activity, for your leadership.

Once again, whenever you take something on, Senator Heinz, you really do it—and do it to perfection.

Chairman HEINZ. Senator Percy, before you leave I want the record to reflect that in spite of your rapidly increasing seniority in the Congress, your great and growing experience, that it is absolutely important that everybody understand that the reason you gave up the chairmanship and the ranking membership of the Committee on Aging was not by any stretch of the imagination because it was a conflict of interest.

Second, I would only observe that I appreciate all the hand-me-downs, both the Alliance To Save Energy and the Committee on Aging.

Sentor PERCY. With institutions and committees like this, it is a hand-me-up.

I just did not think I could do as good a job as you.

[Whereupon, at 5:15 p.m., the committee recessed.].

APPENDIX

MATERIAL RELATED TO HEARING

ITEM 1. BACKGROUND MATERIAL ON HEARING

1. OVERVIEW

The social security disability insurance (DI) program is the Nation's primary source of income support for 2.7 million disabled workers and their dependent (1.2 million). Since 1981, the Social Security Administration (SSA) has aggressively implemented a program of continuing disability investigations (CDI's) to reexamine the eligibility of current DI beneficiaries, in order to ensure that only the truly disabled remain on the rolls. The CDI's were mandated by the Social Security Amendments of 1980.

In the period between March 1981 and November 1983, SSA conducted 1.1 million CDI's. Termination notices were sent to 470,000 beneficiaries informing them that they were no longer eligible for DI benefits. In other words, 45 percent of those subject to a CDI were terminated from the rolls. This high termination rate, in conjunction with the fact that two-thirds of those who appealed to an administrative law judge (ALJ) had their benefits reinstated, has led to widespread concern that the CDI's were being administered in an improper and unjust manner.

Specifically, critics have charged that the CDI's have been conducted hastily and haphazardly, and that the reviews simply do not render accurate or valid conclusions about a beneficiary's capacity to work. Though the problems with the disability review process are very complex and multi-faceted, controversy has centered on four key issues: (1) The extent to which persons can be terminated whose disabling condition has not improved medically since their admittance to the rolls; (2) the quality of the CDI's; (3) the great discrepancy in standards of evaluation between State disability examiners and ALJ's; and (4) the degree to which the mentally disabled have been discriminated against by the CDI's.

In the past year, we have witnessed an unprecedented revolt of the States and the courts against SSA's implementation of the CDI's. Currently, more than half the States have either suspended the CDI's altogether, or conduct them under guidelines that differ from those of SSA. Many States have declared moratoria on the reviews on their own initiative, in open defiance to SSA; others are conducting the reviews under court imposed standards. Several important court decisions have recently been issued which have found SSA's administration of the CDI's to be in violation of the law. Combined, the actions represent a very serious crisis in the disability program.

For the past 2½ years, Congress and SSA had actively negotiated to contruct reponsible legislation to comprehensively reform the disability program. Recently, the Administration has turned its back on these negotiations, and now opposes any substantial legislation. Two major bills, H.R. 4170 and S. 476, are currently pending before Congress. H.R. 4170 is the Tax Reform Act of 1983, and contains a great number of provisons unrelated to disability. The House Ways and Means Committee has reported out H.R. 4170, and it is anticipated to be voted upon in March.

2. WHAT IS A CDI?

The Social Security Amendments of 1980 required SSA to review the continuing eligiblity of all disability beneficiaries once every 3 years, except those designated permanently disabled, which are reviewed every 6 to 7 years. State agency disability determination services (DDS) conduct the CDI's under standards defined by SSA.

The CDI process begins with the state DDS notifying the beneficiary that he or she is up for review, and requesting that the beneficiary submit recent medical information. If the current medical evidence is not detailed enough, or if the beneficiary has had no recent medical treatment, the State disability examiner may arrange for a consultative examination (CE).

The disability examiner evaluates the medical evidence and detemines whether the beneficiary is eligible under current review standards. Those found ineligible are informed they are allowed to submit further evidence. If the State agency, after evaluating the new evidence, still finds that beneficiary ineligible, the beneficiary is notified of that fact, and informed that he or she may appeal by requesting a reconsideration within 60 days.

The reconsideration process is very similiar to the initial review, except that a different team of State agency examiners reviews the case. It should be noted that the beneficiary never encounters in person the DDS examiners at the initial review level. Until recently, this was also the case with the reconsideration stage. This lack of face-to-face contact was the subject of a great deal of criticism, and at the end of 1982, Congress mandated that SSA offer face-to-face evidentiary hearings at the reconsideration level, beginning in January 1984. In the past, initial review decisions were reversed at a rate of only 10 to 15 percent. It is expected that the face-to-face interviews will significantly increase that reversal rate, perhaps to 25 to 30 percent.

In reviewing continuing eligiblility at both the initial review and reconsideration levels, SSA employs a five-step sequential evaluation process. The successive steps are:

Step 1.—SSA must determine whether the claimant is engaging in substantial gainful activity, if he or she is, the claimant is disqualified.

Step 2.—SSA must evaluate whether the impairment is severe; if it is not, eligibility is denied.

Step 3.—If the impairment is severe, SSA must determine whether the claimant's condition "meets or equals" the listing of impairments defined in regulations. The listing is essentially a set of conditions, signs, or symptoms which are deemed to be so severe that their presence alone justifies a finding of disability.

Step 4.—This step really involves two substeps: (a) A determination of the applicant's residual functional capacity (RFC); and (b) an evaluation of whether the claimant has sufficient RFC to return to the mental and physical demands of his or her past work. The RFC assessment requires a practical examination of what an individual can do despite the limitations of his or her disability.

Step 5.—If an individual is determined incapable of functioning in his or her previous job, SSA must evaluate whether that person can perform any work in the national economy, in reference to the applicant's age, education, and prior work experience.

If both the initial review and reconsideration DDS teams completely review the beneficiary under the five-step sequential evaluation and find the beneficiary ineligible, he or she may request a hearing before an administrative law judge (ALJ). The ALJ is responsible for obtaining all relevant evidence for the case, holding a face-to-face nonadversary hearing with the beneficiary, and reaching a conclusion in the case. The ALJ may request testimony from medical and vocational experts and can require the beneficiary to undergo a consultative exam. The individual may be represented by legal counsel, submit additional evidence and produce witnesses.

In the past 2½ years, ALJ's have reversed State DDS decision at a rate of 60 to 65 percent. Initially, approximately 70 percent of those terminated at the State agency level appealed, and recently, that figure has increased to about 90 percent. That increase is the result of legislation enacted at the end of 1982 that temporarily extended benefits through the ALJ stage to terminated beneficiaries appealing unfavorable State agency decisions. That provision expired in December 1983, and unless Congress acts by April 1984, "aid-paid-pending" appeal will cease.

If an ALJ does not reverse the State agency termination decision, the affected individual may request that SSA's appeals council review the case. The appeals council may uphold, reverse, or remand the ALJ decision. If the council affirms the denial of benefits or refuses to review the case, further appeal may be made through the Federal district and appellate court system. In the past 2 years, the Federal courts have been besieged with disability cases. Presently, there are about 40,000 cases pending in the Federal circuit court system.

3. Problems With The CDI's

The periodic review provision of the 1980 amendments were intended to begin on January 1, 1982, with their implementation producing a net savings of only $10 million in the 4-year period between 1982 and 1985. On its own initiative, SSA accelerated the implementation of the reviews to March 1981. The accelerated reviews were included as part of the Reagan administration's fiscal year 1982 budget initiatives, and involved reviewing 30,000 additional DI cases per month beyond the regular review workload. In fiscal year 1980, SSA reviewed the continuing eligibility of 160,000 beneficiaries; in fiscal year 1981, close to 260,000 CDI's were conducted. Once initiated, the volume of the CDI's increased dramatically. Overall, between March 1981 and November 1983, over 1.1 million reviews were completed, and 470,000 beneficiaries were determined no longer eligible for DI benefits.

Not long after the CDI's were implemented in March 1981, widespread concern arose about the quality, accuracy, and fairness of the reviews. Press accounts of severely disabled individuals who had been terminated from the rolls began to proliferate; and constituent reports to Members of Congress established an alarming pattern of questionable terminations. It became clear that close to half of all DI beneficiaries subjected to a CDI were terminated at the initial decision level, often without much warning, and in many instances without much evidence that the individual was not disabled. Significantly, 65 percent of those terminated had their benefits reinstated, if they appealed to an ALJ.

Controversy surrounding the CDI's has focused on a few key issues, which are discussed below.

A. MEDICAL IMPROVEMENT

One of the first problems cited with the CDI's was the fact that beneficiaries were being terminated from the rolls despite the fact that their disabling condition had not improved, or had worsened. In essence, beneficiaries admitted to the rolls under one set of standards were being reevaluated upon a new, more stringent set of standards, and many were being terminated. People who had been placed on the DI rolls 5, 10, and 15 years before the CDI's, many of whom had been led to believe they had been granted a lifetime disability pension, were removed from the rolls with little advance warning or explanation.

The central issue in the debate surrounding the concept of medical improvement is the question of who must bear the burden of proof in the determination of continuing eligibility for DI benefits. Currently, it is the obligation of the beneficiary to prove during the course of a CDI that his or her disability meets contemporary eligibility criteria. How long that person has been on the rolls, or whether or not that person is physically or mentally more fit for employment than when first granted disability status, is immaterial. SSA is obligated only to evaluate cases in relation to present day medical and vocational standards. With a medical improvement standard, the burden of proof shifts from the beneficiary to SSA, and it becomes the obligation of the agency to demonstrate that the individual's disabling condition has improved.

Both comprehensive bills currently pending before Congress, H.R. 4170 and S. 476, include a stipulation that in reviewing continuing eligibility, SSA must employ a medical improvement standard. In both these bills, SSA is required to demonstrate a benficiaries' condition has improved, or that one of four exceptions apply. The exceptions are: (1) That the individual is actually working, and hence should no longer be eligible; (2) the original admittance decision was clearly erroneous or fraudulent; (3) the individual has benefited from advances in medical or vocational technology that allow them to work; and (4) new evaluational techniques show that the disabling impairment is not as severe as originally thought.

B. MENTAL IMPAIRMENTS

One of the most heavily criticized aspects of the CDI's is that the reviews systematically discriminate against mentally disabled beneficiaries. Overwhelming evidence was presented at a Senate Special Committee on Aging hearing in April 1983 that the mentally impaired were among the most likely to be reviewed, and the most likely to be terminated, of the beneficiary population. Two major court decisions, one in Minnesota and one in New York, have found SSA guilty of instituting a covert and illegal policy that singled out the mentally ill for unfair treatment, and that the criteria employed to their capacity to work are deeply flawed. (See section 6, judicial rulings).

The mentally disabled are particularly vulnerable to CDI terminations. Since the evaluation of mental impairments is often subjective, and based on symptomological evidence, it has been easy for SSA to terminate people with mental disabilities. The relevant medical listings are antiquated, and SSA instituted an extraordinarily rigid policy in evaluating the RFC of mentally impaired individuals.

The Government Accounting Office (GAO) has documented that although only 11 percent of those on the rolls are there because of mental impairments, 27 percent of those terminated by the CDI's are of the mentally disabled category. Further, ALJ reversal rates for mental disability appeals cases are much higher (91 percent) proportionally than for the rest of the disabled population. GAO also found that State DDS' rarely have qualified psychologists.

Last summer, Senator Heinz introduced S. 1144, a bill to impose a temporary moratorium upon the reviews of the mentally disabled, pending revision of the regulatory criteria relating to the review of mental impairments. This revision would be completed by SSA in a period of 6 months, in consultation with a panel of experts in the field of mental health. The bill also includes a provision requiring that only a qualified psychologist or psychiatrist make the medical determination in mental impairment cases.

On June 15, 1983, Senator Heinz offered an amendment to a supplemental appropriations bill (H.R. 3069) that contained the basic provisons in S. 1144. The amendment passed the Senate by a wide margin, but was dropped in the House-Senate conference due to a procedural conflict with House rules that preclude the addition of substantive authorizing legislation to appropriations bills.

Subsequently, the major provisions of S. 1144 were incorporated into H.R. 4170, the House bill to comprehensively reform the disability review process.

C. QUALITY OF THE CDI'S

Not long after the CDI's were first implemented, it became clear that there were serious inadequacies in the review process. Without sufficient time, staffing, or resources, State agencies were forced to process far too many CDI's, far too quickly. Further, the manner in which the cases were developed, including the collection of medical evidence, came into serious question.

The simple increase in volume from a routine 160,000 reviews per year to roughly 500,000 CDI's in fiscal year 1983, in and of itself accounts for a major dimension of this problem. The phasein period was much more rapid than intended by Congress, and State agencies sacrificed thoroughness and accuracy to speed and efficiency.

Major problem areas have included: (1) Failure to collect and develop appropriate medical evidence, particularly from treating physicians; (2) over-reliance on cursory consultative examinations, which often fail to account for the longitudinal dimension of a beneficiary's disability; (3) the overly paper-oriented nature of the reviews, and the lack of face-to-face interaction between beneficiaries and DDS examiners; and (4) inadequate notification to beneficiaries of what a CDI entails, what is expected of them, and what range of potential outcomes might occur during the CDI process.

D. UNIFORM STANDARDS

One of the critical problems in the disability review process is that different levels of review are bound to different evaluational criteria. The fact that ALJ's reverse almost two-thirds of all appeals of State agency termination decisions is the most striking indication of this structural flaw.

Currently, SSA issues many substantive policy changes through subregulatory means, such as the POMS (operating procedures), internal memoranda, and Social Security rulings. These changes are not open to public comment and review. To the extent that there are ambiguities or substantive conflicts between these subregulatory standards and published federal regulations, State disability examiners are bound to SSA's administrative directives, while ALJ's adjudicate on the basis of formal regulations.

The root of this inconsistency lies in the statutory exclusion of SSA from the rulemaking requirements defined in the Administrative Procedures Act (APA) of 1946. The APA requires that if an agency intends to propose rulemaking changes, it must publish those proposals in the Federal Register and allow public comment and review. Agencies are allowed to use internal, subregulatory channels to disseminate instructions that serve to clarify or provide interpretive assistance in the concrete administration of the rules. Though HHS has voluntarily agreed to follow APA guidelines, SSA nonetheless continues to promulgate substantive policy changes through subregulatory methods without ever allowing public inspection. The upshot of this practice is that there is no uniformity throughout the disability review and appeals process.

Both comprehensive bills include provisions mandating that SSA follow the public notice and comment requirements of the APA. Advocates claim this would ensure uniform standards at all levels of adjudication, and would allow greater public participation in the rulemaking process.

E. BENEFITS THROUGH THE ALJ STAGE

A key issue that has been involved with the controversy surrounding the continuing eligibility review process is the extension of benefits through the ALJ stage to beneficiaries choosing to appeal State agency termination decisions.

Public Law 97-455, included a provision extending benefits through the ALJ stage, subject to recoupment in the event that the ALJ sustains the termination decision. This provision, however, was adopted on a temporary basis only, pending further congressional action to comprehensively reform the disability review process. "Aid paid pending" was due to expire in October 1983; however, Congress enacted a 67-day extension as part of H.R. 4101. That extension expired in December, and unless Congress acts before April 1984, extended benefits will cease.

4. ADMINISTRATIVE INITIATIVES

In response to congressional pressure and public outcry, the Social Security Administration has implemented a number of its own initiatives to address the problems associated with the disability determination process in general and the CDI's in particular. These initiatives were instituted in two waves; one in late 1982, another in June 1983.

In 1982, SSA began conducting face-to-face informational interviews at SSA district offices to obtain directly from beneficiaries pertinent medical records. The definition of "permanently disabled" was expanded to include additional impairments, and thereby exclude from the CDI's certain groups of beneficiaries. SSA began requiring state disability determination services to collect all relevant medical evidence for the previous 12 months in order to improve the medical evaluation and case development procedures. State agencies are also now required to be more thorough and specific in delineating why beneficiaries are no longer eligible for disability benefits. SSA also initiated a project to reexamine the evaluational process employed in reviewing mental disorders, including testing the utility of multiple consultative examinations in psychiatric cases. Finally, SSA reduced the volume of CDI's in a limited number of States.

In response to many of the problems brought to light by the Senate Aging Committee's hearing on Social Security Reviews of the Mentally Disabled held in April, Secretary Heckler announced a series of administrative initiatives on June 7, 1983. These initiatives included a moratorium on reviews of two-thirds (135,000) of all mental impairment cases pending consultation with mental health specialists on methods to revise and improve the review process for those with mental disorders. Additionally, another 200,000 beneficiaries were designated "permanently disabled," which raised the total exempt from the CDI's to 37 percent of all those on the rolls. SSA also instituted a policy of random selection of CDI cases (rather than focusing on targeted groups most likely to generate terminations), and thereby lowering the termination rate.

5. STATE ACTIONS

A great number of States have revolted against SSA's recent practices and policies relating to the CDI's, and a number of Governors and state agency administrators have imposed moratoria on the reviews. On March 8, Massachusetts Governor Dukakis issued an executive order requiring the State disability determination office to implement a medical improvement standard in reviewing cases, as ordered by a district judge in *Miranda* v. *Secretary of HHS*. Arkansas, Kansas, and West Virginia have similarly implemented review procedures at odds with official SSA policy. In Kansas, Governor Carlin also ordered the reopening and reexamination of all cases terminated since March 1981.

On July 22, 1983, Cesar Perales, Commissioner of the New York State Department of Social Services, suspended reviews pending the establishment of a medical improvement standard. Alabama, New Jersey, Pennsylvania, Michigan, Maine, Illinois, Virginia, North Carolina, Ohio, and New Mexico all have self imposed moratoria [illegible] the reviews. Alaska, Arizona, California, Hawaii, Idaho, Montana, Nevada, Oregon, and Washington have now or at one time initiated temporary or indefinite moratoria. Combined, more than half the States, at the end of 1983, were either not processing the reviews, or were conducting them under standards that varied with official SSA procedures and requirements.

6. JUDICIAL RULINGS

As CDI terminations mounted, thousands of individuals appealed their cases to the Federal courts. The subsequent court decisions have very frequently ruled that

SSA's policies and procedures violate the law. A number of Federal courts have ruled SSA must employ a medical improvement standard when conducting CDI's. Two courts have determined that SSA's reviews of the mentally ill have been administered in an arbitrary and illegal fashion. These legal actions have contributed to the disintegration of national uniformity in the disability program.

A. MEDICAL IMPROVEMENT

Currently, SSA does not use medical improvement as a standard for evaluating the continuing eligibility of disability beneficiaries. However, a number of Federal courts have ruled that this policy is in violation of the law, and that SSA must demonstrate that an individual has improved medically while on the rolls, or that the original decision was clearly erroneous before terminating benefits. This has been the position of the courts in SSI, SSI "grandfathered," and DI cases. Other courts have ruled that once a person has been found disabled, there is a presumption that the individual remains disabled and that SSA bears the burden of proof in determining that the beneficiary is no longer disabled.

The Ninth Circuit Court of Appeals has ruled in two cases—*Finnegan* v. *Mathews* and *Patti* v. *Schweiker* that SSA must incorporate a medical improvement standard into its administration of the CDI's. Courts in virtually every other circuit have since rendered medical improvement decisions unfavorable to SSA.

B. NONACQUIESCENCE

Under the Federal judicial system, decisions of a circuit court of appeals are considered the "law of the circuit" and constitute binding case law on all district courts within the circuit. SSA's policy with regard to rulings with which it disagrees has been to only apply the unfavorable decision to the specific case upon which it was rendered, and not to the entire circuit, or to the rest of the Nation. Hence, the interpretation of the law by the court is not considerd binding for either State agency disability determination services or for Federal SSA offices. SSA also instructs its ALJ's to persist in applying existing agency policy and ignore the court's rulings.

This policy, in combination with SSA's refusal to appeal any unfavorable circuit court decisions to the Supreme Court (which would determine a national standard) has been heavily criticized as arrogant and lawless behavior on the part of a Federal agency. Federal judges in both the Eighth and Ninth Circuits have challenged this policy of nonacquiescence. In *Lopez* v. *Heckler*, a class action suit in the Ninth Circuit, the judge refused to grant a stay, as requested by SSA, of the court's earlier medical improvement decisions. Currently, in the entire Ninth Circuit SSA is required to follow a medical improvement standard. However, in an unusual manner, Supreme Court Justice Rehnquist did grant SSA a partial stay by allowing SSA to avoid making interim payments to those who had been terminated from the rolls in the past who must be reevaluated under a medical improvement standard. The plaintiffs in the case then asked the Supreme Court to overturn the Rehnquist stay, but on October 11, 1983, the court declined to hear the request, thereby allowing the Rehnquist stay to remain in force.

Presently, SSA is not processing CDI's in the Third and Fourth Circuits due to unfavorable medical improvement cases pending resolution upon appeal. Tens of thousands of cases await Federal judicial consideration, and it is clear that courts will continue to rule that SSA must implement a medical improvement standard until the Supreme Court considers this issue (1985 at the earliest).

C. MENTAL IMPAIRMENT DECISIONS

In two important class action suits, *Mental Health Association of Minnesota* v. *Schweiker* and *City of New York* v. *Heckler*, SSA has been found guilty of implementing a covert and illegal policy that systematically discriminated against the mentally ill. Both courts ruled SSA must reopen the cases of all mentally impaired individuals initially denied or terminated from the disability rolls, and reexamine their eligibility under lawful guidelines.

The essence of the illegal and "covert policy" consisted of SSA internal memoranda, returns and reviews to State disability determination officers requiring that if an individual does not meet or equal the listing of impairments, that person can be *presumed* to be capable of performing unskilled work. That policy resulted in a virtual automatic denial of benefits to mentally impaired claimants under age 50.

In New York, District Judge Jack B. Weinstein argued that the result of "SSA's surreptitious undermining of the law" was "particularly tragic in the instant case because of its devastating effects on thousands of mentally ill persons whose very disability prevented them from effectively confronting the system." He also noted that by denying disability benefits to the mentally impaired, SSA simply transferred the costs of their care to the "social service agencies, hospitals and shelters" of New York City and New York State.

Both courts found that SSA was not conducting the fourth step of the sequential evaluation—the evaluation of residual functional capacity—in accordance with the law. The assessment of RFC, if it was done at all, was reduced to a "paper charade" in which any individual who did not meet or equal the listings was assumed, ipso facto, to be capable of unskilled work. Judge Weinstein summarized the implications of this policy in the following passage:

"The Social Security Act and its regulations require the Secretary to make a realistic, individual assessment of each claimant's ability to engage in substantial gainful activity. The class plaintiffs did not receive that assessment. On the contrary, SSA relied on bureaucratic instructions rather than individual assessments and overruled the medical opinions of its own consulting physicians that many of those whose claims they were instructed to deny could not, in fact, work. Physicians were pressured to reach "conclusions" contrary to their own professional beliefs in cases where they felt, at the very least, that additional evidence needed to be gathered in the form of a realistic work assessment. The resulting supremacy of bureaucracy over professional medical judgments and the flaunting of published, objective standards is contrary to the spirit and letter of the Social Security Act."

Key statistics

[Continuing Disability Investigations—March 1981 to November 1983]

Reviewed	1,100,000
Termination notices sent	470,000
Reinstated upon appeal	160,000
Appeal cases pending	120,000
No longer on the rolls	190,000

	Percent
Termination rate at initial decision level	40–45
Net termination rate after appeals process	20–25
Administrative Law Judge reversal rate	60–65

Program statistics	Disability insurance	SSI disability
Total cost 1983	17.9 billion	5 billion
Number of beneficiaries	3.9 million	2.2 million
Average monthly benefit	$435 (individuals) $841 (families)	$235

STATE ACTIONS AND JUDICIAL RULINGS

16 States have declared moratoria on the reviews.

12 States conduct the CDI's under court imposed standards.

SSA has suspended CDI's in the Third and Fourth Circuits (6 States) due to unfavorable judicial rulings.

SSA's Chicago Region and New York are under court order to reopen all mental impairment cases and reinstate terminated beneficiaries, pending re-examination of their cases under lawful guidelines.

LEVELS OF DISABILITY DECISIONMAKING

Level and administered by	Time allowed to appeal to next level (days)	Average time from request to decision (days)
Initial review: State agency (DDS) [1]	60	65
Reconsideration: State agency (DDS) [1]	60	50
Hearing: SSA's Administrative Law Judges	60	184
Appeal: SSA's Appeals Council	60	80
Federal court review: Federal Court System		N.A.

[1] Disability Determination Service.

Note: Illinois termination rate at initial decision level, fiscal year 1982: 47.8 percent.

ITEM 2

MEMORANDUM

TO: All Interested Parties

FROM: J. Antolin, B. Samuels, D. Spector and C. Naper

RE: BDAS Procedures to Evaluate Social Security Disability Claims: A Comprehensive Proposal

DATE:

I. MEDICAL REPORTS

A. Weight to Be Given to Medical Evidence

The most significant evidence of a claimant's disability will be provided by the physician, psychologist, clinical social worker, or other trained person who is treating the claimant on a regular basis. This not only makes common sense, it is also the law. 1/ In fact, because these reports of treating physicians, etc., are so important, courts in Illinois and elsewhere have consistently held that such reports are entitled to controlling weight in determining whether a person is disabled. 2/ This rule holds unless the agency making the decision can show and articulate that the treating

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1/ There are many decisions stating this, the most significant cases are:

Whitney v. Schweiker, 695 F.2d 784, 789 (7th Cir. 1982); Allen v. Weinberger, 552 F.2d 781, 785 (7th Cir. 1977); and Mental Health Association of Minnesota v. Schweiker, 554 F. Supp. 157 (D. Minn. 1982), affirmed, No. 83-1263 (8th Cir. November 4, 1983) (Plaintiff class was claimants in the Chicago region who suffered from a mental impairment).

2/ Id.

physician is biased or can point to contrary objective clinical data where the treating physician's report is not supported by such data. 3/ Nevertheless, BDAS does not adhere to this structure for evaluation of the evidence. New procedures should remove any question -- the greatest weight is given to the treating physician, the consultative is entitled to some weight, and the non-examining physician is entitled to almost no weight.

B. Treating Doctor's Reports

1. Introduction

Given the importance of the treating practitioner's report, the next question is: Whose burden is it to obtain this report? Although the claimant has the technical burden of providing medical evidence of the disability (20 C.F.R. § 404.1522 and § 416.922), the state agency is charged with the responsibility of purchasing existing evidence, (20 C.F.R. § 404.1514 and § 416.914), of developing a full record upon which to make a decision, and of assisting claimants to gather evidence. 4/ This section will address the necessary

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3/ Whitney, at 788-89; Cummins v. Schweiker, 670 F.2d 81 (7th Cir. 1981).

4/ See, GAO Report, No. 14085, Statement of Peter McGough on Social Security Administration's Program for Reviewing the Disability of Persons with Mental Impairments at 19-21 (April 7, 1983). See also, e.g. Cannon v. Harris, 651 F.2d 513 (7th Cir. 1981).

procedures for developing a full record (including treating, consultative and non-examining physician reports) as well as procedures to ensure proper weight is accorded to the various medical reports.

2. BDAS Procedures to Obtain Treating Practitioner's Reports

BDAS procedures presently require that the adjudicator send a written request for information s/he believes is relevant. If the treating physician does not provide a report, the adjudicator may attempt to obtain information over the telephone and prepare a "phone contact" report summarizing the doctor's answers to the adjudicator's inquiry. The exact questions asked are unknown. The form usually is not signed by the doctor whose statements appear;

rare occasions, a conscientious adjudicator will inform a claimant that his/her doctor is not cooperating. Whether all of these steps are taken depends on the adjudicator drawn by the claimant. In fact, it is not uncommon on reconsideration that none of these steps are taken.

To eliminate the arbitrariness inherent in the present process, to ensure that each claimant has her/his record developed fully to the extent possible, the following procedures are necessary:

a. A letter should be sent to every treating physician or practitioner which:

(i) advises him or her of the clinical evidence necessary, the importance of such evidence and the deadlines, if any, to submit it; and of the availability of a fee to defray some of the reproduction costs;

(ii) provides the impairments listing and any form questionnaires that pertain to the impairment claimed by the claimant;

(iii) contains a residual functional capacity report with an explanation of terms; and

(iv) contains a psychiatric residual capacity report in mental illness or retardation cases.

b. A request should be sent to every hospital listed by the claimant for a copy of the entire inpatient, outpatient, or clinic records (not just admission, discharge and lab tests).

c. A second letter should be sent to every treating physician or practitioner whose report is not received in twenty-one days. In this letter, the potentially dire consequences for the claimant's application for benefits should be indicated and a deadline should be set. In addition, a copy of this letter should be sent to the claimant with a note informing him or her that the report is very important and encouraging the claimant to contact the doctor.

d. In all of its correspondence to treating physicians and practitioners, the BDAS should both clearly identify the information sought regarding specific impairments and request that the treating physician identify any other impairments. This includes asking the physician to assess whether pain or other nonexertional limits are consistent with the diagnosed impairment.

e. If the record is only missing a specific test result, or if clinical data is not in the form anticipated by the listings, a specific request/order for the test should be directed to the treating physician advising him/her that SSA will pay for the test before a consultative is ordered.

C. Consultative Examining Physician's Reports

The state agency is charged with the responsibility of arranging consultative examinations of the claimants by doctors. The primary purpose of these examinations is to resolve inconsistencies in the medical records; the secondary purpose is to document the existence of alleged impairments with clinical data. These examinations are paid for by the Department of Health and Human Services. The reports resulting from them are geared to the disability regulations (the listings of impairments). While this makes it easier for the adjudicator to assess whether an impairment matches the listing, the report is not entitled to controlling weight if due, obviously, to the fact that a consultative doctor sees the patient only once for less than an hour and is incapable generally of making an assessment of a claimant's capabilities over a substantial period of time.

BDAS in Illinois routinely orders a consultative exam on every claim. 5/ This is done because these reports are easier to obtain. 6/ In addition, throughout the state, BDAS relies on "disability mills" to perform the consultative exams. In Chicago, the Consultative Examination, Inc. network of doctors (operating out of several locations but primarily St. Elizabeth's Hospital), 7/ Medical Consultants, Inc. [Busse Highway, Western Ave.] and Union Medical Center are the largest Chicago area mills. In downstate areas such as Champaign, the

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5/ Id.

6/ Id.

7/ Consultative Examinations, Inc. ("CEI") is the largest beneficiary of government funds for consultative exams in Region V. CEI was also the subject of a very critical GAO report. GAO report HRD 83-65, SSA Needs to Protect Against Possible Conflict of Interest (June 10, 1983). Among other things, the GAO found that the Chief Medical Advisor to the Social Security Administration's Chicago Office and several other medical personnel had a financial interest in CEI creating the appearance of a conflict of interest -- if not an actual conflict -- that CEI is providing the "evidence" for Social Security to deny benefits ensuring continued referrals to CEI. In fact, Dr. Berendi is still conducting examination for his employer, Social Security, on behalf of his company, CEI, according to client reports.

six state mill of Thurman and Thurman operates; 9/ other such disability mills can be found throughout the state. These disability mills will frequently see 20 to 30 claimants, per doctor, at one location a day.9/ The reports, despite the necessarily abbreviated examination, will generally be a three to six page comprehensive report reviewing every bodily system and containing a detailed history. Close scrutiny of these reports reveals a consistent "word processor" pattern to these reports belieing their purported individualized findings.10/ This is further verified by claimants who frequently complain of inadequate and cursory examinations conducted by doctors who are not appropriate specialists. 11/ Thus, a claimant with lupus, a multi-system

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8/ Thurman and Thurman were found guilty of fraud in the preparation of their medical reports for the state agency in Tennessee. Bush v. Schweiker, CCH Unemp. Ins. Reptr. ¶ 17,933 (1982).

9/ At these mills, clients frequently have reported having to wait several hours to see a consultant Doctor who will examine them for fifteen minutes or less.

10/ In addition, these reports often contain substantive errors, such as wrong names, sex, height, weight, etc. -- errors that would be unlikely if a complete physical had been done. Obviously, such errors raise questions as to who was examined or the nature of the exam

11/ In addition, CEI in St. Elizabeth's has a waiting room that is not accessible to individuals on wheelchairs. On a typical day this CEI facility is overcrowded, is not smoke free in the non-smokers section, is without appropriate chairs for orthopedic patients, and is so heavily overbooked that claimants wait two hours or more to be seen by the doctor for fifteen minutes. In essence, the CEI offices more resemble an emergency room than a doctor's office where the doctor sees patients by appointment only.

physical disease, was referred to a psychiatrist; a claimant with back fusion surgery was referred to an internist; x-ray tests are ordered for disc impairments; and intelligence evaluations are made by psychiatrists (who do not perform I.Q. testing as do psychologists).

BDAS should be required to:

1. Adopt criteria for selection of consultative examiners with particular emphasis on matching specialization to the impairments;

2. Adopt criteria establishing when the purchase of a consultative exam is necessary, i.e., to resolve conflicts in the medical evidence or to document an impairment(s);

3. Place a limit on the total number of referrals any one doctor may receive in one day to eliminate reliance on high volume providers or "disability mills;"

4. Adopt procedures to eliminate a consultative doctor from referral lists on the basis of claimant complaints, conflict of interest, or evidence of fraud in report preparation;

5. Establish procedures for claimant evaluations of the consulting doctors or periodic, unannounced site visits by DORS personnel;

6. Require BDAS adjudicators to send past records to the consultative doctor and require that doctors to review these records prior to examining the claimant and identify the

records received in the report.12/

7. Advise the claimant of the reasons for arranging consultation, the nature of the exam, the information or medication to be brought, and the tests to be conducted, as well as to provide a list of the records provided to the doctor;

8. Require that consultative doctors must either be fluent in English or speak the language of the claimant to guarantee full communication; in the alternative, BDAS should arrange a qualified interpreter to assist the doctor;

9. Send all consultative reports to treating physicians for comment.

D. Non-Examining Physician's Reports

The non-examining physician is a BDAS staff person. This doctor's role is to explain difficult concepts or complex cases to the adjudicator who lacks medical training. 13/ Recently, BDAS has relied on this doctor to make the definitive evaluation of a claimant's residual physical and/or mental capacities. BDAS has done this in compliance with an SSR issued by HHS. 14/ Leaving the absurdity of this aside, the

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12/ This serves two purposes: (1) it ensures that a consultant will be aware of all the impairments a claimant has since many claimants are not aware or able to advise the doctor about their impairments, and (2) it provides the treatment and test results history to a consultant to enable him/her to make a better examination.

13/ Richardson v. Perales, 402 U.S. 389, 28 L.Ed. 2d 842 (1971).

14/ Social Security Ruling 82-30

heavy reliance placed on these reports must be halted in order to comply with the law as set forth by the Supreme Court in Richardson.

The procedures should include:

1. Recognition of the primary purpose of the non-examining physician as explaining complex or complicated aspects of the claimant's records, including interpreting tests not adequately explained;

2. The principle that little or no weight is due to any assessments by the non-examining doctor of the severity [15] or residual capacities of the claimant.

3. A rule requiring the non-examining physician to state the materials upon which s/he bases his/her interpretation and to explain the reasons for the interpretation whenever s/he reports upon residual capacities or explainscomplex aspects of a claim.

E. The Claimant's Access To His/Her Record

The present strict BDAS policy against release of medical records makes it difficult for the claimant to obtain his/her administrative record. This must be rectified. A claimant must be provided a copy of all the medical and vocational records in the file or be afforded an opportunity to review his/her record not more than 7 days after the request is made to the BDAS claims adjudicator or 10 days after the request is made to the local Social Security district office. Furthermore, a decision should not be made on reconsideration until the claimant receives the record and either indicates that there will not be more evidence forthcoming or fails to contact the adjudicator within 14 days after the record is sent. This policy must be explained in a cover memo to the claimant.

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[15] If there is any question as to the severity of the claimant's impairments, the objective standard outlined below provides adequate guidance to the BDAS adjudicator.

II. MENTAL DISORDERS

A. Primary Issues

Claims involving mental disorders (organic brain dysfunction, functional non-psychotic disorders, psychotic disorders, drug or alcohol dependence, and retardation) pose particular problems at the state agency level. As the district court stated in Mental Health Association of Minnesota v. Schweiker ("MHAM"): "Chronic mental illness is characterized by an exquisite sensitivity to stress and a decrease in coping skills." 16/ Consultative psychiatric examinations are often cursory and based on faulty or scanty psychiatric histories. Too often consultative examinations do not involve any of the

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16/ Mental Health Association of Minnesota v. Schweiker, 554 F. Supp. 157, 162 (D. Minn. 1982).

recognized standardized tests which objectively reveal organicity, retardation or severe personality disorders. See 20 C.F.R. Part 404 Subpart P, Appendix 1, § 12.00. Analyses of the residual functional capacity of the mentally impaired claimant are often not based on a realistic assessment of the claimant's capacity of the real competitive workplace. Moreover, they are too often made by personnel without specialized skills in the diagnosis and treatment of mental illness or retardation.

B. Use Of Consultative Examinations

Where an impairment involves low intellectual functioning, any evidence of organicity, loss of memory, loss of concentration, or loss of ability to calculate, psychometric testing should be ordered by the BDAS in addition to, or in lieu of, psychiatric diagnostic interviewing. Similarly, where the impairment involves a personality disorder, schizophrenia or a schizo-affective disorder, psychometric testing and projective testing should be ordered in conjunction with psychiatric diagnostic interviewing (e.g., the Minnesota Multiphasic Personality Inventory or those portions of the WAIS-R selected by the test administrator).

Where psychiatric examination is ordered, the interview should include a factual description of the claimant's daily activities, a statement identifying the source for and the nature of the claimant's medical and social history, a statement of the source of any other information provided during the course of the evaluation, and a statement of all medical and other reports used in the assessment.

As noted above at § IC-6, consulting examiners must be provided with the claimant's medical reports which have been collected by the BDAS prior to evaluating the claimant. Consulting examiners also should be asked to recommend other types of evaluations which might be appropriate for the claimant given the examiner's findings. Finally, the report of the consultative examiner must be provided to the treating practitioner for comments.

C. Residual Functional Capacity Findings

Assessment of a mentally impaired claimant's residual functional capacity must be based on a realistic assessment of the claimant's capacity to function in the real world competitive workplace (MHAM). These remaining capacities must be evaluated in accordance with the individual's ability to meet the minimum standards of a normal competitive work setting on a full-time, sustained basis.

This assessment should be sought first from the treating physician or other professional therapist (e.g., psychologist, clinical social worker). This assessment should also be sought from the consulting psychologist or psychiatrist. This assessment should not be sought from a non-examining physician, particularly when that individual's medical specialty is not in the area of mental health.

The evaluation of residual functional capacity should normally include consideration of observations of work limitations made outside of a formal medical or psychological evaluation, such as workshop evaluations, work adjustment evaluations, past work successes and/or failures, and such other relevant reliable information that may be available from sources other than medical providers.17/

In assessing residual functional capacity, substantial weight must be given to information provided by treating sources. Caution should be exercised in relying on information or conclusions of non-examining physicians or physicians who have examined the claimant only once, particularly where such reports are based solely on diagnostic interviewing and not on the results of standardized psychometric or projective testing. Where the opinion of the non-examining or single-examination physician is contrary to that of a treating source and is accepted by the decision maker, a written statement of the rationale for relying upon such opinion must be provided. Treating sources should be provided an opportunity to review and comment on information or opinions advanced by non-treating sources and on the rationale for relying upon such information and opinions where they are

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17/ Minnesota Mental Health Association v. Schweiker, 554 F.Supp. at 168.

contrary to those of the treating source.

Where an individual has a limited residual functional capacity because of a mental impairment, but his condition does not meet or equal an impairment listed at Section 12.00, 20 C.F.R. Part 404, Appendix 1, it must not be presumed that such individual has the residual capacity for simple unskilled work. A realistic assessment must be made of the claimant's residual ability to engage in basic work related activities, including the ability on a sustained basis to deal with the public, co-workers, and supervisors; to tolerate stress over time; to understand and remember instructions; to concentrate; and to travel to and from work alone on a regular basis in a timely manner.

D. BDAS Adjudications And Consultants

Claims primarily or in part based on mental disabilities must be handled by agency adjudicators with particular training in evaluating mental impairments. These adjudicators must work in conjunction with medical advisors who are themselves specialists in the area of psychiatric and psychological disorders.

Evaluations of mental disability claims should not be made by physicians whose areas of expertise do not entail the diagnosis and treatment of mental disorders.

III. ASSESSMENT OF CLAIMS

A. Staff Structure

Presently there are approximately 610 BDAS adjudicators who decide claims. There are approximately 67 part-time and 4 or 5 full-time doctors with whom the adjudicators may consult during the initial and reconsideration process. Claims at each stage are assigned to adjudicators either randomly or geographically, except that an adjudicator does not decide a claim at both stages.

Staff specialization should be required by assigning adjudicators to a specific body system; claimants whose primary impairment involves a certain body system would have their claims reviewed by the appropriate adjudicator. Two additional units should be set up: claims involving a combination of impairment would be referred to a separate unit of adjudicators trained in assessing the impact of combined impairments, and claims involving diseases affecting multiple body systems (e.g. AIDS, lupus, etc.) would be assigned to adjudicators trained to evaluate these. Consulting doctors should also be categorized by specialty, if any, and claims of impairments associated with the specialty should be referred to them.

In addition. within each body system, certain adjudicators should be assigned only to initial reviews and others only to reconsideration reviews so that objectivity is more closely maintained.

B. Existence of Severe Impairment

The Social Security Act provides that a person will be entitled to benefits if the impairments are so severe that he or she is unable to do either his/her past work or any other work which exists in significant numbers in the national economy. 18/ HHS, in turn, has interpreted this to require a severe impairment. 19/ The existence of a severe impairment is tested by whether or not a claimant's ability to perform basic work activities has been impaired. 20/ Basic work activities are defined as the ability to lift, carry, push, and pull objects; to stand, sit and walk; to understand, carry out, and remember simple instructions; to use judgment; to respond appropriately to supervision, co-workers and usual work situations; and to deal with changes in a routine work setting. 21/

18/ 42 U.S.C. §§ 423(a) and 1382(c)(a)(3)(A)(B)(C).

19/ 20 C.F.R. §§ 404.1520(c), 416.920(c).

20/ 20 C.F.R. §§ 404.1521, 416.921.

21/ 20 C.F.R. §§ 404.1521(b) and 416.921(b).

The rules should be:

1. Where reliable evidence shows that the claimant's ability to perform any *one* of those basic work activities listed above is impaired, the impairment must be considered severe. 22/

2. Objectively, if the evidence of record shows that the claimant can no longer do his/her past work because of an impairment, then it is a severe impairment. Similarly, if a claimant is left with the residual functional capacity to do only sedentary or light work, 23/ or has a non-exertional

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22/ A determination that an impairment is severe is not determinative of disability; rather it only guarantees that a claimant's impairments and limitations will be assessed in light of vocational factors such as age, education and work experience, as well as realistic assessments of residual capacity to perform basic work activites. *See* 20 C.F.R. §§ 404.1520 and 416.920.

23/ By definition, residual capacity to do only light or sedentary work equals limited ability to do the physical work activities. Ability to perform light work is defined as follows: ability to lift 20 pounds maximum with frequent lifting or carrying of objects weighing up to 10 pounds. Even though the weight lifted may be only a negligible amount, a job is in this category when it requires walking or standing to a significant degree, or when it involves sitting most of the time with a degree of pushing and pulling of arm or leg controls. To be considered capable of performing a full or wide range of light work, an individual must be capable of performing substantially all of the foregoing activities. Sedentary substantially all of the foregoing activities. Sedentary is defined as: the ability to lift 10 pounds maximum with occasional lifting or carrying of such articles as dockets (e.g., files), ledgers, and small tools. Although a sedentary job is defined as one which involves sitting, a certain amount of walking and standing is often necessary to carrying out job duties. Jobs are sedentary if walking and standing are required no more than 2 of 8 hours and other sedentary criteria are met.

impairment which reduces his/her ability to work, then a severe impairment must be found to exist.

3. Findings of no severe impairment can only be made if the medical evidence establishes the existence of only "a slight neurosis, slight impairment of sight or hearing, or other slight abnormality or a combination of slight abnormalities." 24/

4. Not severe findings must not be made where a claimant's age, education, and work experience would prevent the individual from engaging in any kind of work. 25/

C. Vocational Work-Ups

When a claimant suffers from a non-exertional impairment, 26/ the regulations known as the medical vocational

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24/ 43 Federal Register No. 229, p. 55357-58 (November 18, 1978).

25/ Id.

26/ A non-exertional impairment is one which limits a person's ability to work but does not affect his/her physical strength. Examples include: pain, mental illness, fatigue, weakness, blindness, deafness, deficits in eye hand coordination or fine manipulation, incontinence, swelling, seizures, etc.

guidelines, or the grid (20 C.F.R. Part 404, Subpart P, Appendix 2) may not be applied, 27/ and a real world vocational work-up is necessary. 28/ Whenever evidence of a non-exertional impairment is found in a claimant's disability file, BDAS should be required to order a vocational work-up of the claimant including actual workshop testing, such as a work product evaluation, to determine appropriateness of response (behavior), communication skills, ability to handle pressure, concentration, coordination and related physical capacities. Evaluations should be based on at least one week of such

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27/ Cummins v. Schweiker, 670 F.2d 81 (7th Cir. 1982); Holliday v. Schweiker, 563 F. Supp. 1272 (N.D. Ill. 1983).

28/ Mental Health Association of Minnesota v. Schweiker, 554 F. Supp. 157, 168 (D. Minn. 1982), affirmed, ___ F.2d ___ (8th Cir. 1983).

workshop testing. Referrals for psychological testing should be made where appropriate. BDAS currently relies on a vocational assessment that does not fulfill this requirement.

D. Pain

Pain, a non-exertional limitation, is a well recognized component of many medical conditions but it can rarely be objectively verified by medical tests. Often such pain by itself can be disabling. 29/ For this reason, allegations of pain must be considered as a separate factor in disability claims. If pain is alleged by a claimant, BDAS must address this factor in its decision and consider all evidence in the record including laboratory findings, treating doctor's opinions, reports of claimant's complaints in doctors' reports, hospital records, test results, Social Security disability reports, and claimant's statements. If allegations of severe pain are contained in the record with no supporting medical

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29/ E.g. Nelson v. Heckler, 712 F.2d 346 (8th Cir. 1983);Baerga v. Richardson, 500 F.2d 309, 312 (3d Cir. 1974), cert. denied, 420 U.S. 931 (1975); Garcia v. Califano, 463 F. Supp. 1098, 1103 (N.D. Ill. 1979); Atkins v. Califano, 446 F. Supp. 1017, 1020 (N.D. Ill. 1978).

findings, psychological testing should be ordered. 30/

E. Medical Improvement

The Federal Circuit Court of Appeals in Illinois has held that disability benefits should not be terminated without a positive showing of medical improvement or that the original finding of disability was in error. 31/ BDAS should be required to follow the law and not terminate existing claims without either the requisite medical evidence of positive improvement or substantial evidence that the original disability determination was in gross error.

IV. FACE TO FACE RECONSIDERATION CONFERENCES

A. Introduction

Face to face reconsiderations have been touted as the innovation that will make the process much fairer. In its

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30/ SSR 82-58.

31/ Cassiday v. Schweiker, 663 F.2d 745 (7th Cir. 1981). Other courts have concurred: Patti v. Schweiker, (9th Cir. 1983); Kuzmin v. Hecker (3rd Cir. 1983); Miranda v. Schweiker, (2d Cir. 1981); Dutson v. Schweiker, (4th Cir. 1983); Tavjillo v. Schweiker, (D. Ariz. 1983); Graham v. Heckler, (W.Va. 1983); Simpson v. Heckler, (Fla. 1983).

present proposed form, this reconsideration process presents a myriad of practical and constitutional problems. As presently proposed, face to face reconsideration conferences will only occur for persons who appeal a termination or cessation of their disability benefits and BDAS intends to affirm the termination. By the time an initial decision is made to terminate benefits, SSA has some evidence (generally a consultative exam) on which that decision relies. This is the evidence SSA will start out with if a request for reconsideration is filed; indeed, because the reconsideration process is to be handled with speed, it may be the only evidence available up to the day of the reconsideration interview. SSA has proposed regulations which would authorize BDAS to prepare a detailed summary of the evidence at the reconsideration stage for the Conference Officer ("CO"). It seems, under the circumstances, more reasonable to have the BDAS "summary" of the record prepared when the initial decision to terminate is made. This summary should then be sent to the claimant/recipient with the notice of decision to terminate benefits so that s/he knows both what was considered (and therefore possibly what is missing) and what the reasons were for termination (i.e. the issues) enabling him/her to make a more educated assessment of whether to appeal for a reconsideration. It would also provide the claimant more time to obtain new evidence or old evidence not considered by the

BDAS; thereby, making reconsideration a significant review of the decision and not a "rubber stamp."

B. Time Frames

SSA also has proposed time frames for the face to face reconsideration conference proceeding to be completed, namely 60 to 75 days from request to decision. Most of this time is alloted for BDAS review, re-organization and summarizating of the file before it goes to the CO. Much time will be wasted, however, in internal file shuffling which consequently will detract from the time available to claimants and their representatives for preparation and presentation of the case at the reconsideration conference. Pursuant to the proposal set forth hereafter, BDAS would forward files to the CO with all due speed as soon as a request for reconsideration is filed. The CO would be responsible for preparing the file and a new summary (if that is necessary); reviewing the record; holding the conference; and, in appropriate cases, developing further evidence. This would also allow the claimant's representative to gain access to the file that much sooner. The following time frames are therefore proposed for this system:

1. BDAS has ten days to schedule or docket a claim for a reconsideration conference from the date a request is filed. The actual date of the interview will be scheduled at least 30 days from the date the claim is put on the CO docket by the BDAS. In this way, a claimant is provided 30 days advance notice of the conference.

2. Within 5 days after putting the case on the CO docket, BDAS must ship the file to the CO. This will allow the claimant/representative approximately twenty days to review/copy the file.

3. If the distance to the CO prohibits a personal visit by the claimant, s/he should be able to obtain photostatic copies of the record in the mail from the CO by request.

4. The CO must issue a decision within 5 working days of the reconsideration conference, unless additional time to submit evidence is requested by claimant or ordered by the CO; if that is the case, then the decision must be issued within 5 days following the receipt of the additional evidence.

The above time frames would enable reconsideration decisions to be issued well within the projected 60 day period, while allowing the longest possible time for claimant preparation, potential post-hearing development, and preparation of the decision.

C. Title of Face to Face Conference

The conference should not be called a hearing because to do so will confuse recipients as well as IDPA in the administration of interim assistance and discourages those persons who lose from pursuing appeals to an ALJ. For this reason, it should be designated as a reconsideration "conference."

D. Scope of Conference

The Conference should extend to the following factors:

1. The CO should consider all medical and vocational factors, especially if such criteria were applied in the initial assessment of disability that resulted in the original award of benefits.
2. If only medical factors are considered, the standard applied tends to be Listing of Impairments, which is not proper. This must be forbidden.
3. The CO must assess whether medical improvement has been established. If so, then the CO must apply the sequential evaluation to the remaining impairments, [32] *i.e.*:

    a. severity;
    b. impairment listings;
    c. ability to do past work;
    d. medical-vocational regulations;
    e. non-exertional limitations,
    20 C.F.R. § 404.1520 and 416.920.

E. Post Hearing Evidence

The SSA proposed rules limit evidence to that "which has a direct bearing on outcome of hearing" *and* "could not be obtgained earlier." 45 Fed. Reg 36832(a).

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[32] *Cannon v. Harris*, 651 F.2d 513 (7th Cir. 1981).

This is unnecessarily restrictive especially if the client is unrepresented and does not know what this means and the client does not have access to BDAS summary or meaningful advance access to file to ascertain the evidence in it. Therefore, the procedure should be that any evidence submitted should be incorporated into the file and considered by the CO.

F. Notice

1. Require 30-Days Advance Notice

Proposed federal regulations require scheduling to be computerized; as a result a 30-day notice is feasible. Advance notice of this length will reduce requests for extensions to a new date necessitated by unavailability of counsel; unavailability of witnesses; inability to obtain medical evidence in time; and inability to make transportation arrangements. In addition, such advance notice will eliminate an inherently absurd aspect of the present regulations. Under proposed federal regulations both the BDAS notice of conference and the claimant's request for delay must be made within 10 days before hearing. Obviously, one can't be expected to request delay on the same day the notice is mailed. Requests for delay (postponement) should be granted on a showing of good cause as defined by SSA regulations -- any more restrictive standard is unjustified.[33]

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[33] Pub. L. 97-455, § 5.

2. Contents of Notice

The notice to the claimant advising him/her of the conference should include all the following information:

a. time, date, place of conference;

b. telephone number(s) of hearing officer(s);

c. right to seek postponement upon good cause (with a definition or examples) and time frame for such request;

d. the right to seek a change in location of hearing and the circumstances under which such a request will be granted;

e. statement of nature, contents and sources of evidence already considered;

f. right to submit additional evidence; importance of doing so; nature of evidence that can be submitted;

g. reason(s) that claim was terminated;

h. statement of issues and a summary of evidence to be used by hearing officer should accompany notice;

i. right to appear and testify and to bring witnesses;

j. right to be represented, including a list of free legal services and private bar referral numbers;

k. statement regarding status of benefits (i.e., loss of SSI benefits) if reconsideration is adverse;

l. right to see case file and when and where to do so;

m. right to travel reimbursement -- conditions and procedures to obtain it prior to travel.

G. Pre-Conference Development

1. Access to File

The Federal Regulations at 20 C.F.R. 404.916(b)(2) and 416.1416(b)(2) provide that recipients have a right "to review evidence and present additional evidence." This is meaningless unless file is accessible well prior to conference so the representative knows what evidence there is and can obtain evidence not already of record. Additionally, the right to counsel is empty if counsel's lack of access impairs his or her ability to effectively represent the client -- more extended access to file is necessary if rules governing post-hearing submission of evidence are restrictively drawn or applied. See IV.E, supra. Therefore:

a. The file must be made available to the client or a copy sent to him/her 20 days prior to conference;

b. Conference officers shall provide photocopying facilities to claimant/representatives.

2. Subpoena Rights

CO must allow adverse witnesses to be subpoenaed. 34/ Witnesses include any consultants used by CO to review and/or comment on file whether in general or specific terms, expecially where BDAS has relied on either reports or interpretation of reports of either non-examining or non-treating consultants to terminate benefits. 35/ There is no other effective means of assuring meaningful opportunity to claimants if the right to confront adverse witnesses is not provided. 36/

3. File Preparation:

The CO should prepare the file for reconsideration conference.37/ If BDAS both makes the decision

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34/ Public Law 97-455(5) implies necessity of subpoena by the language "advise beneficiaries ... of the importance of submitting all evidence ...." § 5(2).

35/ Richardson v. Perales, 402 U.S. 389 (1971).

36/ Goldbery v. Kelly, 397 U.S. 254 (1969).

37/ Pub. L. 97-455, § 4(a)(2)(c).

to terminate and prepares the reconsideration summary, the CO is likely to be so isolated from the evidence of record as to never look at it and will to limit consideration to BDAS summary. To avoid this pitfall, the following procedures are necessary:

(a) The CO should be given the responsibility of preparing the summary;

(b) The CO must identify in the file any expert with whom s/he has consulted in evaluating the case;

(c) The summary of evidence with a statement of the issues should be sent to recipient with a notice of scheduling of conference so s/he knows what the issues are;

All evidence in recipient's file should be incorporated in the record before thew CO. Pub. L. 97-455, § 4(a) specifies that face-to-face reconsideration "hearing" applies where determination has been made that physical/mental impairment has ceased, does not exist, or is not longer disabling. The standard for review of cessation in this jurisdiction is medical improvement. 38/ SSA has issued instructions which would limit evidence in record "to include only current information ... medical reports pertainming to a prior application which has been determined and which is not involved in the current issue (whether to continue benefits) should not be included in hearing packet because the original file establishing why benefits were awarded will not be in the record. Since the SSA instruction is merely another aspect of SSA nonacquiescence in the law, it should be countered with a legal requirement that the file must contain the past record and current evidence in order to assess whetgher medical improvement has occurred.

H. Development and Processing Procedures

While it is to be hoped that face-to-face reconsideration will not cause further delay in the administrative process, speed should not prevail over care and accuracy of the decision-making process.

Every effort should be made to fully document the claims file so that a full and fair adjudication results. Therefore:

1. An affirmative obligation should be placed on the CO to provide a full and fair inquiry into the issues should be adopted.

38/ Cassiday v. Schweiker, 663 F.2d 745 (7th Cir. 1981). See also 48 Fed. Reg. 36833.

2. Time frames as outlined in subsection B above should be reasonabale to allow complete:

   a. development;
   b. assessment;
   c. testimonal evidence;
   d. and, if necessary; post-hearing activities.

3. Regarding scheduling of hearing and production/output quotas:

   a. The CO should not be overbooked.

   b. Production expectations of CO should be realistic, allowing sufficient time for full hearings and accurate decisions.

   c. Each CO should be encouraged to read the complete file (not just the summary) prior to each conference (this is accomplished if CO must prepare a new summary) and to encourage full participation by the claimant and witnesses.

4. Hearing time goals have been proposed by SSA follows:

Hearing Officer review of file before hearing:	20-30 mins.
Hearing	30-45 mins.
Write decision	20-25 mins.

Completion of 4-5 conferences and decisions per day.

Because these time goals are oppressive both to the client and the CO, more realistic standards should be adopted. These include:

   a. The conference should take as long as necessary to allow full coverage of the issues;

b. Decisions should be issued as soon as is practicable. In the absence of post-conference development 5 days seems reasonable; when post-conference development is required, 5 days after the evidence is complete.

I. Location of Conference

The Conference must be "reasonably accessible" to the claimant. Pub. L. 97-455, § 4(a)(2)(c). In determining what is "reasonably accessible:"

1. Consideration must be given to the nature of claimant's impairment, his/her mobility, the availability of transportation from claimant's home to the conference site, difficulty of obtaining and cost of such transportation and any other special factors related to claimant's mental or physical health.

2. Recipients who have special problems which impair the ability to travel must be notified of their right to seek a change of location and how to do so.

3. Reimbursement for travel expenses should be available in advance of the conference when requested and information of its availability and method by which to obtain same should be included in notice to claimant.

4. 75 mile rule is arbitrary and should be reduced to "within the county" location. Even this rule should not be applied rigidly in special cases as defined by § I.1 and 2. above.

5. Conference sites must be so arranged that claimant's right to privacy and dignity are not compromised.

J. Reversal by CO Supervisors Should Be Limited In SSI Cases (and SSA Cases Where Benefits Are Not Paid Pending Appeal)

Proposed SSA regulations, 20 C.F.R. §§ 404.918 and 416.1418, permit a supervisor who was not present at the reconsideration conference to reverse the decision of the CO when it is determined that there was an abuse of discretion, error of law, or that the decision is not supported by substantial evidence.

Because SSI benefits will be terminated if the recipient loses the reconsideration conference and because some SSA recipients may not be receiving benefits pending appeal, due process will be violated if the decision is in fact made by someone not present at the conference. Therefore, the reversal of CO at a reconsideration conference, if allowed at all, should only be made by the stated criteria when the decision is reversed in favor of the claimant.

ITEM 3. STATEMENT OF LAURA GUILFOYLE, ILLINOIS ALLIANCE FOR THE MENTALLY ILL, EVANSTON, ILL.

The inadequacies of the Social Security Disability review process have been well-documented. Since March 1981, 355,000 people have been cut off of Supplemental Security Income and Social Security Disability Insurance. Although the mentally ill make up only 11 percent of the 2 million disability beneficiaries, they have been involved in 25 percent of the cut-offs.

The General Accounting Office found in a study of 1,400 appealed cases that 9 out of 10 terminations of mentally ill persons were reversed by administrative law judges. For many of these individuals, it was their first face-to-face interview.

The Social Security Administration has been challenged in court in class action suits on behalf of mentally ill persons in Illinois, Indiana, Michigan, Minnesota, Ohio, Wisconsin as well as New York and North Carolina. In each of these cases, the Social Security Administration has been ordered to reinstate mentally ill persons cut from SSI and SSDI rolls. U.S. District Judge Jack B. Weinstein charged in *New York City* v. *Heckler* that from 1978 until last year, the federal government had a "fixed clandestine policy against those with mental illness."

The statistics above show the magnitude of the problems with the Social Security Disability review process, but they do not show the pain and suffering of persons whose benefits have been summarily denied. The Illinois Alliance for the Mentally Ill, an advocacy and support group for families, patients, and expatients, has received numerous phone calls from mentally ill persons and their families who are distraught because SSI or SSDI benefits have been terminated. The most we could do for these people was direct them to a legal aid clinic or public defender.

The Social Security Administration has made a few changes in the disability review process because of the public outcry. But this is not enough.

There is a need for long-term reforms in the Social Security Disability review process. Such legislation has been proposed in both the U.S. House and Senate. The Illinois Alliance for the Mentally Ill supports legislation including the following reforms:

1. Clear and convincing evidence of medical improvement which enables a person to perform substantial gainful activity must be shown before a person's disability benefits can be terminated.

2. The combined effects of impairments may be considered in determining whether someone can work, even if none of the impairments, considered separately, is severe.

3. A finding of disability must be based on a realistic evaluation of the individual's capacity to meet the demands of competitive work on a sustained basis.

4. The Social Security Administration may not base a conclusion that someone can work solely on employment in a sheltered or non-competitive work environment.

5. The standards and procedures for evaluating mental impairments must be revised to be consistent with current medical and scientific knowledge. The eligibility of initial applicants evaluated under current criteria and those terminated since March 1981 must be redetermined.

5. PL 97-455 provisions relating to continuation of benefits and Medicare eligibility through the administrative law judge hearing must be made permanent.

6. The complete medical and vocational history, including all evidence in the file from prior evaluations must be considered.

7. The Social Security Administration must contact recipients scheduled for a continuing disability investigation and determine whether they will need help in complying with instructions for the review. This help must be provided by the Social Security Administration or the person must be referred to a local agency or organization who can assist the person.

8. Disability hearings must be held at a location and in a building reasonably accessible to a disabled applicant.

9. Decisions on medical eligibility benefits must be made only by appropriately qualified professionals. Determinations of mental impairment can only be made by a psychiatrist or psychologist.

10. The Social Security Administration must issue detailed regulations setting forth the standards to be used by state agencies and federal personnel to identify consultative examiners and refer individuals to them for medical examinations and mechanisms for monitoring the quality of consultative examiners' referrals and reports.

These reforms are necessary to ensure that the Social Security Administration will deprive disabled Americans of disability benefits once again when the public outcry has died down.

ITEM 4. STATEMENT OF TIMOTHY HAGAN, COMMISSIONER, CUYAHOGA COUNTY, OHIO, ON BEHALF OF THE NATIONAL ASSOCIATION OF COUNTIES[1]

Good afternoon Mr. Chairman. I am pleased to be here today on behalf of the National Association of Counties (NACo).[2] We appreciate the opportunity to testify at a time when county, State and Federal Government representatives, and our colleagues in the private sector, seek better ways to administer the programs that serve our disabled citizens.

County officials have a particular interest in the disability problems that the special committee is addressing, and I am glad to share some of our concerns with you. Nationwide, county governments will provide over $25 billion this year in health and welfare services. Although there is no uniform pattern across the country, almost all counties fund and administer some aspect of the social safety net that supports mentally disabled persons, such as: community mental health centers; board and care or nursing home facilities; social rehabilitation programs; adult protective services; and general assistance to support needy people who qualify for SSI or disability insurance benefits.

It is the county government, as providers of last resort, that picks up the pieces when mentally disabled persons (and others) fall through the cracks of some Federal or State system. Some rather graphic examples of such systems failures are coming to our attention at the local level. The impact is seen in our hospital emergency rooms, our county clinics, our police stations, crisis intervention centers, and acute psychiatric facilities. The results are being felt by our county programs and budgets, as well as by our needy citizens.

Many counties are not equipped to step in and provide for all the needs of disabled persons when Federal assistance is disrupted. For others, the burden of local assistance which they must bear represents a shift of Federal fiscal responsibility to county budgets. Given the fiscal condition of counties today, this shifting of Federal costs is an intolerable burden. Fortunately, it can be relieved by an improved Federal approach to disability determination and review.

The National Association of Counties has long supported the Federal programs for disabled people under Titles II and XVI of the Social Security Act, commonly known as social security disability insurance (SSDI) and supplemental security income (SSI). We have also consistently supported the premise that these programs should benefit those disabled people who are truly unable to maintain themselves in substantial gainful activity—whose disability precludes their being able to get a job and keep it. In the interest of the program's integrity, it is clear that there must be periodic reviews of beneficiary claims to assure that the disability continues.

As reports have come in from counties around the country the past year or so, however, it has become clear that federally-initiated efforts to weed out beneficiaries who are employable, by speeding up reviews and tightening eligibility for disability benefits, have resulted in excessive termination or denial of benefits to persons who in fact, are not employable and who remain disabled. For various reasons, people with mental disabilities have been particularly adversely affected. For the individual client unable to work, the loss of disability benefits—and corresponding health benefits—can provoke personal tragedy. For the county governments who must step in to provide the needed services, it represents another step toward fiscal catastrophe. Let me cite examples from representatives of counties in several States in this region:

Newaygo County, Michigan, a rural county of 40,000 people, has spent approximately $10,000 for general relief, mental health, and community services for persons cut from the SSI and social security disability roles. This does not include the costs of medical services provided by the county as provider of last resort. Social services, which paid more than $50,000 in general relief payments for these disabled persons, was able to help about 80% return to the roles on their first appeal. Social services in continuing to assist the remainder through the appeals process and, if the disabled are not determined eligible, the costs for general relief will be even higher. Mental health staff has also made an effort to identify these persons dropped from the roles. they have identified 4 percent of their 500 clients as disabled and helped each of them regain their benefits. Not only are county dollars being spent to provide services, but county staff time is being spent to help the disable receive the Federal benefits for which they were entitled but from which they were cut.

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[1] The Chairman of NACo's Health and Education Steering Committee, of which I'm a member, is John Stroger, a Commissioner here in Cook County.

[2] NACo is the only national organization representing county government in America. Its membership includes urban, suburban and rural counties joined together for the common purpose of strengthening county government to meet the needs to all Americans. By virtue of a county's membership, all its elected and appointed officials become participants in an organization dedicated to the following goals: improving county government; serving as the national spokesman for county government; acting as a liaison between the Nation's counties and other levels of government; and achieving the public understanding of the role of counties in the Federal system.

In Ramsey County, Minnesota, where there were over 100 new general assistance enrollees by fall, 1982, as a direct result of loss of SSI or SSDI benefits, the county initiated a special advocacy program with a projected savings in cost-shifts to the county of approximately $150,000. Many of the new general assistance applicants were mentally disabled; all seemed clearly unable to move into competitive employment. By the beginning of 1983, however, the situation had improved to the point that Ramsey County cancelled its plan to expand the advocacy service. At least in [Federal] Region V, the combination of face-to-face interviews and—one way speculate—the impact of the pending litigation, has slowed the process and made it more responsive to individual factors warranting attention.

The National Association of Counties has considered various approaches to ensure that disability programs support those who are truly eligible, and that mentally disabled people are not inadvertently singled out for overly restrictive procedures. At its meeting on March 1, 1983, the NACo board of directors approved reform of the present SSI and SSDI systems that would incorporate the following principles:

Individuals may not be terminated from disability programs unless there is clear and convincing evidence of significant improvement, employability, or total failure to cooperate in the review process without good cause;

Disability reviews should consider all available vocational information as well as medical information;

People with mental impairments should be provided with assistance in completing the review process if necessary and should have a vocational assessment based on the realistic experience of competitive employment;

Provisions of Public Law 97-455 relating to a reasonable pace of reviews and continuation of medicare eligibility through the hearing level, scheduled to expire in October 1983, should be made permanent; and

Reviews and hearings should be in buildings and at locations and conducted in a manner that makes the proceedings accessible to the client.

We would also support efforts to include consultative examinations specific to the mental disability, for people so affected. It is significant to note that while problems continue, there has been some improvement over the past few months. While not as dramatic as the improvement in Ramsey County, other counties report that the interim reforms of Public Law 97-455 and the Social Security Administration's requirement of face-to-face contact in the continuing disability investigations program have slowed down the rate of cost shifts to counties. We strongly support this Congress' attention to these problems and the search for permanent reforms through needed legislative changes.

Mr. Chairman and members of the committee, we will welcome the opportunity to work further with the committee to provide additional information and to discuss the impact of legislative proposals. If it would be helpful to the committee, we would also be able to provide information on specific cases that illustrate the need for the kinds of reforms we support.

ITEM 5. STATEMENT OF CATHERINE WILSON, CHAPTER SERVICE DIRECTOR, CHICAGO-NORTHERN ILLINOIS CHAPTER, NATIONAL MULTIPLE SCLEROSIS ASSOCIATION

My name is Catherine Wilson. I am a Chapter Service Director which includes supervision of programs related to multiple sclerosis patients, their families and those associated through employment, social activities, and routine activities of daily living. Included in Multiple Sclerosis Society programs is the selection of clinical services and referral of clients to those services which best meet their current needs. Currently, the Chicago-Northern Illinois Chapter of the National Multiple

Sclerosis Society includes five clinical resources as part of the organization on going program.

The testimony which is included in the final document includes in part attitudes and testimony provided by Dr. Floyd A. Davis, neurologist and director of the MS Center—Rush-Presbyterian Medical Center and Professor of neurology at Rush-Presbyterian Medical School at Chicago, Illinois. Additionally, this testimony includes data and opinions which are the results of individuals and group counselling and client support activities maintained by this Chapter over the past threc years of my directorship. Currently, this Chapter serves an estimated 17,500 Multiple Sclerosis Chapters in the Northern Illinois area. Of this number, more than 7,800 are recorded in statistics maintained by this Chapter, affiliated clinical resources and membership maintenance listing.

The National Multiple Sclerosis Society, through its Medical Advisory Board, has been working with the Social Security Administration for about three years regarding the current Social Security Administration criteria for establishing disability for those with MS. It is the view of those of us specializing in neurology and multiple sclerosis that the disability criteria used by the Social Security Administration (SSA) is too narrow and does not reflect current medical judgment relative to the disabling nature of multiple sclerosis accompanied by motor and sensory fatigue. The current limited medical description is that substantial numbers of persons with disabling multiple sclerosis, are initially denied Disability Insurance coverage or when called upon for review must go through the most difficult process of proving the symptoms of fatigue. At the initial determination fatigue might not be a major problem. On review it maybe the only major symptom present. Therefore, causing a definite problem for the reviewers we do not have specific numbers of cases that fall into this category, but by far the largest number of complaints our Chicago office receives about disability determinations is in the medical definition of multiple sclerosis (MS) and its failure to properly recognize motor and sensory fatigue.

My testimony today relates generally to the point of the appropriateness of standards and policies used by Social Security for determining disability, particularly standards and policies that involve medical determinations both at the initial step upon review. The issue involved is whether these standards, policies and definitions adequately reflect current medical opinion and practice and, if not, how such current practice and opinion can impact upon the SSA system.

Multiple sclerosis is a case in point regarding the medical criteria used by the agency and the process by which these criteria are established. My testimony also raises the more specific question of when MS should be determined to be disabling from a medical standpoint. And thus needing medical review board for the review process.

BACKGROUND DATA AND INFORMATION

Multiple sclerosis has been recorded to affect some 130,000 Americans and we believe this figure may be upward of 250,000. The annual incidence of MS is estimated at about 8,000 or about 4.2 persons per hundred thousand (Citation: Baum and Rothschild, "Incidence and Prevalence of MS," Annals of Neurology, Vol. 10, No. 5, November 1981, page 420). It is not among the most prevalent disabilities, therefore, but its effects are severe. It is a disease which generally affects those between 20 and 40, (Ibid.). The disease affects more females than males by a ratio of 1.7 to 1 (Ibid.). Interestingly, the prevalence of MS is much higher in regions above the 37th parallel than in those below it (Ibid.). Because the disease is most prevalent among those 20 to 40, most persons with MS have had a work history, and are eligible for Social Security Disability Insurance. The disease is life-long in duration.

MS is a disease of the Central Nervous System (CNS), acquired in youth. The first clinical symptoms and signs usually appear after a dormant, symptom-free interval of five years or more. The most characteristic pathological feature of multiple sclerosis is patchy areas of inflammation and destruction of myelin, the material which forms an insulating sheath around nerve fibers, followed by scarring scattered throughout the white matter of the brain and spinal cord. There is a wide range of severity involved. Acute MS is mild, seldom recognized, compatible with normal life expectancy and may not be disabling. The great majority of cases life between these extremes, with the most frequent cases experiencing intermittent periods of symptoms and signs (exacerbation) followed by a period of improvement (remission). A smaller number of cases, usually of relative late onset, have slow, steady progression with spastic paraparesis as the most common manifestation.

Exacerbations occur in nearly all cases and vary in frequency, duration, character and severity and commonly show evidence of more than one area of the CNS involved. Remissions similarly vary in duration and to the extent of improvement. With time, a pattern of the clinical course is sometimes established but generally the course is not predictable in individual cases. The degree of improvement diminishes after each bout of symptoms, in most cases develop significant, permanent disability and impairment of neurological functions within five to ten years after the first period of symptoms.

The symptoms and signs of MS may involve vision, balance, coordination, muscle power, sexual function and bladder and rectal functions. In a minority of cases, impairment of memory and intellect may occur. The symptom of fatigue with reduction stamina is almost universal and frequently is, in itself, incapacitating.

In the review process, the understanding of initial diagnosis for multiple sclerosis can be lost because of the change in the persons' symptoms. The diagnosis of MS is based on clinical judgment. Laboratory tests, including CSF gamma globulin determinations, evoked potentials and CAT scanning are helpful adjuncts but are not specific.

THE DISABILITY DETERMINATION PROBLEM

The major problem in the disability determination process for those with MS involved initial determinations of eligibility and the physical phenomenon of fatigue. The medical definition of MS in the SSA guidelines, referred to as medical listings, limit MS narrowly and does not include the condition of motor and sensory fatigue. (The motor system is that involving movement.) Therefore, if this symptom is the only one present at the time of review the MS person who initially was approved can now be denied.

As noted earlier in the testimony, MS is a disease in which the fatty covering of nerve fibers is destroyed. This is referred to as demyelination. This demyelination leads to short circuiting which slows or blocks the passage of nerve impulses. This results in paralysis and spasticity. These aspects of the disease are covered in the medical listing definition. Demyelination may also result in substantial physical fatigue caused by a failure of the nerves to faithfully conduct the normal number of impulses. This fatigue is caused by the disease and will result in substantial reduction of motor function comparable to paralyses and paresis.

Fatigue is a universal complaint and phenomenon in patients with MS. It can involve both the motor and sensory systems and is characterized by a progressive loss of function which, in most patients, recovers with relatively short rest periods. In the motor system, it can affect the ability to perform rapid, alternating movements of the hands and is particularly noticeable with attempts at ambulation. In the visual system, patients can develop a fatiguing of vision whereby the vision actually blurs or becomes nonexistent for varying periods of time. As mentioned previously, all of these phenomena, while reversing on rest, recur with persistent activity. The degree of activity necessary to produce the fatigue phenomenon can be mild to moderate in nature. It can be shown that with continued stimulation of demyelinated nerve fibers, there is a progressive decline in the ability of the fiber to conduct trains of impulses.

Many patients who demonstrate the fatiguing phenomenon are seriously disabled. They often show other evidences of inability to function such as a reversible severe worsening of motor and sensory functions with small increases in body temperature unassociated with fatigue. These individuals have large numbers of nerve fibers which are in a state of borderline function and which suddenly turn off when the body temperature is only elevated one or two degrees. It is believed that these borderline functioning fibers are probably also the same population of fibers which are responsible for the fatiguing phenomenon also described above. Thus, in a sense, many patients with MS appear like the tip of the iceberg. Often, what is seen on simple inspection represents only a small part of the overall difficulty that the patient is able or likely to experience under usual working or even simple activities of personal hygiene.

This might be completely overlooked at the review process because of a change in other symptoms. In summary, then, fatigue can occur in patients with MS who appear on surface to have minimal or even not apparent disability. The phenomenon is now recognized as characteristic of the illness and often represents a major disabling symptom. It is an effect uniquely associated with MS. It is not a mental or emotional disorder. As a physical phenomenon, it is identical to fatigue in myasthenia gravis, recognized by SSA as a major disability. It is extremely important to be recognized as a severe symptom at the review time for Multiple Sclerosis.

The current medical listing definition of MS is essentially as follows, and the 1982 proposed revisions continue this definition:

"Multiple sclerosis with either: (a) significant and persistent disorganization of motor function (paresis, paralysis, tremor or other involuntary movements) resulting in sustained disturbance of movement or gant and station; or (b) visual or mental impairments (chronic brain syndrome)."

Many persons with disabling MS do not have the characteristics of either (a) or (b) present at the time of review. They are not paralyzed nor are they visually or mentally impaired. However, they are disabled from the physical phenomenon I have referred to as motor and sensory fatigue. It is related directly to the disease which often renders them unable to work as if they were paralyzed or had the other facets of MS that are recognized in the medical listings.

In these cases, there generally is a determination made by those assuming disability that the person does not fit the definition in the medical listings and is not severely impaired. This medical judgment results in an adverse determination. The critical and compassionate questions of work history, education and vocational capacity are never reached.

In our particular case, we believe that the weight of opinion of the nation's medical experts in MS clearly supports a new definition of MS which reflects the motor and sensory fatigue factor. The phenomenon is physical and physicians can objectively observe it. We know enough about the disease to understand what is physically causing this disabling conditions. In many cases, it is severely disabling and makes sustained work of any kind impossible. These are not cases of lazy people who are "dogging it." They are physically ill individuals experiencing serious effects of this disease. The adverse disability determination itself often causes these people serious emotional and mental problems for they are characterized as malingerers who do not have a serious impairment, when, in fact, they do.

We hope this Senate Special Committee will express its concern to the Social Security Administration about this specific problem and assist us in solving it. We also hope that this Committee will seriously consider reforms of the process by which medical criteria and policies are established and current medical data and opinion received and reviewed.

To summarize:

(1) Disabling MS patients are not being assessed appropriately under the current disability determination system.

(2) The narrowness of medical listing criteria relative to MS is largely the cause of this problem in that motor and sensory fatigue resulting from a failure of impulse conduction is not recognized by the listings.

(3) The system of establishing medical standards and policies is not effective in dealing with changing medical opinion and data.

ITEM 6. STATEMENT OF HORTENSE LEVKOVITZ, WILMETTE, ILL.

I will give a very brief history of my involvement with social security disability insurance.

In February 1973, my son was 19 years old, and became ill with manic depressive disease. In the past 11 years, there have been multiple hospitalizations for long periods of time, and involvements with psychiatric rehabilitation agencies. It was through one of these agencies, Thresholds, that we became aware of social security disability.

We made application. After much correspondence, we gathered all the necessary information, such as documentation of my son's psychiatric history. There were one or two rejections, and in 1976, there was acceptance.

There have been periodic reviews of my son's condition, and after submission of further documentation substantiating his disability, his benefits have continued.

If my husband and I did not review our son's mail periodically, especially during his long hospitalizations, he would have permanently lost his benefits.

By the very nature of the disease, mental illness is an inhibitor of responsible behavior.

The correspondence from Social Security, at best, is difficult for the average, well, literate individual to comprehend, let alone those people suffering with a mental disability.

During the late summer of 1982, my son had a face-to-face interview with a psychiatrist designated by Social Security. The questions asked were simple. Then my son was asked how he felt, to which he answered "fine," and if he thought he could work, to which he answered "sure." The psychiatrist, of all people, should know about denial of their illness on the part of psychiatric patients. At the time of this examination, my son was escalating, and shortly afterwards, in September 1982, he was admitted to the hospital for 6 months.

We do feel a face-to-face interview is important. However, we feel there must be more, such as medical history and hospital records being available to the examining Psychiatrist for his review prior to an interview of this importance.

During that 6-month hospitalization, my son's benefits were terminated, effective November 30, 1982. We received notification of this in December 1982, even though the notification was dated October 19, 1982. Needless to say we were very distressed and did not know were to turn. We are not in a position to take on the financial burden of our son's illness.

At about this time, we received some campaign literature from Congressman Sidney Yates' office, stating there was help available for handling problems with Social Security. We called and spoke to a woman named Edie Englehardt. I explained the situation, and she immediately called Baltimore and had my son's file "red-flagged." Ms. Englehardt continued working on the problem and kept me informed as to the progress. During that time there was no further communication from Social Security.

Ms. Englehardt informed me of the reinstatement of my son's benefits prior to receiving the retroactive benefits, or any notification from Social Security. This was the end of February or the beginning of March 1983. In April 1983, we received notification from Social Security that my son would be subject to further review of his disability for as long as he receives benefits.

At this point I must tell you that there are many other families faced with the dilemma, and not knowing where to turn. Many people have hired attorneys, which they cannot afford, to assist them. Many beneficiaries are still waiting to hear from Social Security. I always advise the families in my support group to contact their Congressman for the most help.

As a parent of a mentally ill son, and as a founding member of the Illinois Alliance for the Mentally Ill, listed below are some suggestions for change.

1. Continued face to face interviews with qualified psychiatrists.
2. Psychiatric history and medical records available to the interviewing psychiatrist prior to the interview.
3. Conversation with the attending psychiatrist prior to the interview.
4. On time mailing of notifications.
5. Understandable correspondence.
6. Information readily available to beneficiaries who have been terminated.
7. Benefits must be continued during the determination process.

Extension of benefits is running out. Something must be done to prevent this.

ITEM 7. STATEMENT OF MICHAEL GRICE, CHICAGO, ILL.

I am 27 years old and a quadriplegic due to a motorcycle and a diving accident at the ages of 15 and 23. The diving accident confined me to a wheelchair, which I am in right now.

I think that the organizations that are all working together are doing a fantastic job. But, when it comes to the State level, they're not getting the cooperation that they need. It makes it unbearable for a disabled person to live under the standards the State has set, particularly if you have to live off $25 if you are living in a State institution.

To me, there is some bureaucracy involved when it comes to judging who is able to work and who is not. There seems to be a lot of conflict of interest among these professional people who look at your records and make that decision. But hopefully, we will in the future be able to accomplish the goals that we have all set out to accomplish—all over the United States, not just in the State of Illinois. I feel that there must be combined unity among the 50 States. You cannot break it down into one individual State as the State of Illinois is doing at the present time.

As it stands now, I feel that we're going to have to keep on having more of these meetings and to get more people at high levels every time. Hopefully, the Senators can get the support that they need. Action speaks louder than words.

The situation is causing a lot of people here today—organizations—a lot of frustration because they're not able to help their clients. It's incredible to see the percentage of clients that are in institutions and turned down because of poor judgment by some of the medical profession. I'm hoping to see a change, let's say, in the next 2 years or so.

ITEM 8. STATEMENT OF CHRISTINE LA VERGNE, PARALEGAL ADVOCATE, LEGAL ADVOCACY SERVICE, GUARDIANSHIP AND ADVOCACY COMMISSION, CHICAGO, ILL.

The Illinois Guardianship and Advocacy Commission is a State agency mandated to ensure the rights of the mentally and physicially disabled citizens of Illinois. The commission was created to enforce State laws such as the Mental Health and Developmental Disabilities Code and the Confidentiality Act and related State and Federal laws. Those disabled citizens experiencing difficulty in obtaining and retaining OASDI/SSI benefits are just one part of the clients the commission serves. The division of the commission that has the most contact with people facing termination or denial of disability benefits is the Legal Advocacy Service (LAS); which represents handicapped people in regard to legal problems related to their handicaps. The bulk of LAS's caseload concerns the rights of institutionalized disabled citizens. However, the commission supports the right of the disabled to live in the least restrictive setting and knows that many of the severely disabled cannot live in the community without cash assistance from the OASDI/SSI programs, as well as medicare/medicaid benefits that are available only when the SSA has determined a person to be disabled. Therefore, the commission has committed its resources to representing people at OASDI/SSI disability hearings, assisting people with the initial and reconsideration stages of the disability process and referring people we can not directly serve to other sources of legal assistance.

During the period July 1, 1982 through June 1983, the LAS assisted a total of 220 people with OASDI/SSI problems and from June 1983 to present we have provided assistance to 119 people with OASDI/SSI problems. Specifically, the LAS has represented 92 people at disability hearings since July 1, 1982. This representation is limited in terms of quantity, but it has enabled the commission to be aware of how the SSA disability system works and does not work. Approximately 75 percent of our representation is for people initially denied disability benefits and 25 percent is for people whose benefits were terminated. The majority of clients represented are mentally impaired. Approximately 45 percent of our clients are mentally ill, 45 percent are developmentally disabled and 10 percent are physicially handicapped.

It has become clear to us that the problems our clients encounter in obtaining disability benefits are the result of wrongful Federal SSA policies and procedures that deny disabled persons who cannot work benefits they need. In addition, the lengthy appeal process is difficult and damaging to our clients.

The two main problems the commission has seen again and again are:

(1) Our clients are terminated from benefits without the State disability detemination agency obtaining complete medical and vocational profiles. For example, the LAS represents a 30-year-old woman named Inez who completed 10 years of special education and last worked in June 1981 in a sheltered workshop. Inez was initially granted SSI benefits by an ALJ decision rendered in November 1981. The ALJ found that Inez is mildly retarded, has various psychiatric afflictions and is status-post ileostomy. The ALJ also noted that Inez's psychiatric problems are so serious that in the month prior to the decision she mutilated her abdomen due to an inability to cope with her ileostomy. On February 9, 1983, the SSA sent Inez a SSI termination notice advising her that her benefits would stop because her ulcerative colitis, back pain and anemia were not severe. The SSA did not even look at the impairments that were the basis for the initial award of benefits, let alone consider whether those impairments had medically improved. Fortunately, Inez filed a timely request for hearing and continues to receive her SSI benefits. Unlike many other mentally impaired people facing OASDI/SSI terminations, Inez was fortunate enough to have a social worker who follows her progress in the community and advised her to file an appeal. Inez is illiterate and her social worker has taught Inez to show all letters to her. Inez appeared before an ALJ on September 28, 1983. Inez is still waiting for her hearing decision. Similarly, the LAS represents another client, Eli, who suffers from mild mental retardation, epilepsy and emotional problems. Eli received a SSI termination notice stating that his epilepsy was not severe. SSA failed to consider Eli's other two impairments.

(2) Our clients are denied or terminated from benefits because the opinions of treating medical providers are not considered by the SSA. LAS represents Mike, a 28-year-old man with a college degree who last worked in April 1982 as a hospital orderly. He has been diagnosed as suffering from manic-depressive illness and was hospitalized four times in 1982 for this condition. Mike applied for SSI benefits in January 1983. In the same month, he began participating in a hospital psychiatric day program. The treating psychologist at the day program referred Mike to the commission because he had received his initial SSI denial notice and his therapy

sessions were becoming focused on his lack of money rather than his emotional problems. The SSA sent Mike to a psychiatric consultant after he filed his application. The consultant found Mike to be severely disabled. Despite past hospitalization records, current reports from the day program indicating the seriousness of Mike's condition and a confirming consultant psychiatrist's report, Mike was again denied benefits. The reports from the treating medical providers indicated Mike was delusional, manic, antisocial and could not withstand the pressures of work on a sustained basis. The State disability determination agency rejected these reports and instead relied upon a psychiatric assessment completed by a nonexamining State agency medical consultant which indicated Mike could perform simple, unskilled work. Mike requested a hearing on March 23, 1983. His hearing was held on July 12, 1983. A favorable ALJ hearing decision was issued August 24, 1983. Mike did not begin to receive regular monthly SSI benefits until January 1984 and has not yet received his lump sum payment for back benefits. During 1983, Mike moved three times due to lack of money. He lived on $144/month general assistance for most of 1983. Mike was unable to participate in the hospital day program on a regular basis because he did not have the money for public transportation to and from the program. The same information the ALJ reviewed and found to be evidence that Mike's condition met a listed impairment in the SSA regulations was before the SSA at the initial and reconsideration levels. The one year dealy in awarding benefits forced a sick young man to cope with harsh financial circumstances and SSA red tape. The 1-year delay set back Mike's treatment and ultimately, his return to the work force.

The above examples of termination are SSI beneficiaries. The situation becomes much harsher for a title II beneficiary whose benefits are terminated. The title II beneficiary no longer has the protection of continued benefits pending an ALJ hearing decision. The commission strongly urges the Congress to pass legislation that will afford title II beneficiaries continued benefits pending an ALJ decision. Equally important is legislation that addresses issues such as a termination standard and SSA's policy of nonacquiescence.

ITEM 9. STATEMENT OF BOBBIE WALKER, CHICAGO, ILL.

My name is Bobbie Walker, I am 61 years old. I began receiving social security in August 1973. I became ill in 1971. I exhausted all money and my employer encouraged me to apply. He advised me I had paid for this and it was not charity. I had hesitated but had no opiton. I depend on this money to survive.

I had an excellent job. I worked through the ranks into a position of management. I was a teletype operator, phone operator, phone supervisor, customer service instructor supervisor and an instructor. I traveled as a trouble shooter to different States to teach and handle problematic conditions in customer service departments. I developed the first instruction book ever produced for the company. I loved the job, worked with wonderful people. The future of the job was excellent with advances assured—surely not a job anyone would want to leave. It was exciting, interesting and rewarding.

While driving at a point from Chicago, where I was visiting back to the new location in another State, I had a seizure. My car went into a ditch. I didn't know what had happened. I was brought back to Chicago, the closest point. Eventually after many tests, I was told that I had grand mal epilepsy. I knew nothing about this disorder, and still hoped to return to work but medication did not stop the seizures and painfully I realized I could no longer return.

Social Security states that my "seizures do not significantly interfere with my daily activities." My seizures interfere with my entire life. Social Security also states that I should avoid heights and machinery. This is not the worse that could endanger me and I think it is incredible to try to simplify my condition as such.

It would help if someone in the agency of the State that make these decisions had suffered as I have, and do. Maybe they would understand. But then they could understand. But then they would not have been allowed to have a job in the agency in the first place.

Crossing streets, riding public transportation, falling down stairs, having my belongings taken or lost while I'm totally unaware of what is happening around me is worse.

Seizures render me helpless, unable to even get help. I am subject to ridicule, humiliated, embarrassed, avoided and shunned. It has taken a toll in confidence because I never know when I will have a seizure. Added to this I lose bladder control. I am disoriented, bewildered, confused and dazed and at the mercy of others who have thought I was an alcoholic or drug addict. I suffer extreme headaches at times and I am disoriented for 3 to 4 days following a seizure.

I would obviously have more control over my daily activities at home and I'm not prey in the streets.

I am not a sideshow freak and I have as much self pride as anyone. I cannot change my disfunctioning body. If I could I would and certainly would have no need to beg for anything from anyone to survive, which I am doing.

Social security states my disability discontinued and my education was part of the consideration and determination they concluded. I fail to see the equivalency. Education has nothing to do with the job market for epileptics. Most able bodied people are unable to find work. Does education, age, or work experience, make one less ill?

I am unable to do gainful substantial work. I am daily restricted by my impairment.

At home I have removed sharp objects that have injured me in the past, had steps cushioned and covered after I had a bad ankle sprain from a fall that took 2 months to walk normally again. I removed objects from high shelves so as not to climb to reach. I put medications and clock close to bed for availability. I have soap, towels, etc., to assure cleanliness when I find it difficult to care for myself. I keep quick food or fruit available. I try to maintain independent attitudes and self help is utmost important, and I don't complain to anyone about my illness.

On January 9, 1984, I appeared at my hearing before Judge Richard Sprague. I was terrified, and a nervous wreck. I am now awaiting the results of this hearing and praying for myself and others like me that this nightmare will end.

ITEM 10. STATEMENT OF MARTHA A. McSTEEN, ACTING COMMISSIONER, SOCIAL SECURITY ADMINISTRATION, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Mr. Chairman and members of the committee, I am pleased to submit this statement on the progress we have made in improving the Social Security Disability decisionmaking process. I would like to make clear at the outset that the administration opposes enactment of disability legislation. We believe that the administrative and legislative reforms already accomplished make further legislative changes unnecessary. Therefore, the very high cost of the disability provisions in H.R. 4170—about $6 billion in the first 5 years—are unacceptable, especially at the present time when the safety margins of the OASDI trust funds are relatively small.

Improving the Disability Process

As you are well aware, the implementation of periodic review of disability beneficiaries mandated by the Congress in 1980 brought to light the need for a number of fundamental changes in the disability decisionmaking process. It became clear that the review process was creating hardships for some beneficiaries and that these hardships had to be alleviated—either administratively or legislatively. Beginning early in 1982, we began implementing a series of administrative reforms to make the disability decisionmaking process more responsive to the needs and concerns of the disabled. In addition, the Congress enacted some important reforms in the disability process. While the early reforms went far toward making the CDR process more fair, humane and effective, additional experience, along with consultation with those concerned with the disability program, pointed the way to the further major reforms that Secretary Heckler announced on June 17, 1983.

I want to mention that a number of these reforms improved the initial disability decisionmaking process as well. Because of the public attention given to the continuing disability reviews (CDR) over the last few years, the progress we have made with the initial disability claims process has perhaps been overshadowed.

Two of the key legislated reforms (included in P.L. 97-455) were the continued payment of benefits during appeal (extended by P.L. 98-118) and a face-to-face evidentiary hearing at the reconsideration level. The provision to continue payment of benefits during appeal to an ALJ hearing relieved the anxieties and financial hardships of many whose disability benefits have been terminated. About 93 percent of those who appeal the decision to terminate benefits have elected continuation of benefits.

A basic issue to be resolved is whether to extend or modify the continued payment provision because it has expired. Under P.L. 97-455 as extended, continued payments can be offered only to beneficiaries who were determined no longer disabled before December 7, 1983. As we have in the past, we still support continued payment of benefits through the first evidentiary hearing in the appeals process.

Incidentally, based on the results of our pilot project on providing an evidentiary hearing at reconsideration, we believe this program will improve beneficiary satisfaction with the disability process. Since States expressed an interest in conducting the reconsideration hearings, we have given them the opportunity to do so. We believe that giving the States the option to participate will strengthen the positive relationship between the States and the Federal Government in the administration of the program. Preliminary responses from the States indicate that nearly all States are interested in conducting the reconsideration hearings.

I might mention that the reconsideration hearing process is being implemented using State hearing officers in States that are ready to conduct the hearings. In other States, Federal hearing officers will temporarily conduct the hearings until the States are ready to do so. (Federal hearing officers will conduct the hearings in the few States that have declined.)

Let me now briefly note the most important of our administrative reforms to date. These reforms were designed to make the program more responsive to the needs of beneficiaries while still assuring that we fulfill our obligations to Congress and the taxpaying public to administer the program in an efficient and effective manner.

We reduced the number of beneficiaries to be reviewed every 3 years by expanding our definition of permanent disability. Now roughly 40 percent of disabled worker beneficiaries are exempted from the 3-year review.

We suspended the review of mentally impaired beneficiaries with functional psychotic disorders until the criteria for reviewing these cases could be revised. These beneficiaries were the most prone to incorrect terminations. Part of the problem in the review of these cases is that diagnosis, treatment and standards of measurement of these disorders are very difficult.

We begin each CDR with an interview in a local Social Security office in order to explain the process to beneficiaries and advise them of their rights and responsibilities.

We initiated a top-to-bottom review of disability policies and procedures in consultation with appropriate experts and the States, and have increased our efforts to seek the advice of the medical community on the entire disability process. There are several groups currently reviewing both physical and mental impairment issues, and they have recommended a number of significant actions.

I am particularly pleased with the work done by the group revising the criteria for mental impairments in the listings. The group, which includes outside experts as well as SSA and State agency personnel, is close to completing its work on evaluating mental impairments and will be submitting its recommendations to us very soon. We hope to have a revised mental impairment listing published for public comment by April.

Also, we asked a workgroup to consider how we might make greater use of work evaluations in mental impairment cases to assess a person's ability to work. We believe that these evaluations could be very helpful in providing a better picture of what an individual is able to do. A report detailing this workgroup's recommendations will be published shortly in the Federal Register and comments invited.

Another workgroup is exploring ways of improving the quality, content and timeliness of psychiatric medical evidence.

We have entered into a peer review contract with the American Psychiatric Association. This should be in place by the time the revised mental impairment criteria are in effect.

CONSIDERATION OF ADDITIONAL LEGISLATIVE REFORMS

Before moving to a discussion of specific legislative proposals, I want to comment briefly on the cost of the disability provisions in the bill (H.R. 4170) approved by the Committee on Ways and Means on October 21, 1983. The bill would cost about $6 billion over the five fiscal years 1984 through 1988. This includes OASDI program and administrative costs plus SSI, Medicare and Medicaid costs. I should emphasize that the estimate represents costs only through FY 1988. These costs assume that under the language of the bill the courts would be likely to require the medical improvement to be applied retroactively, requiring reopening of cases decided over the past 3 years. (Applying the medical improvement standard only prospectively would result in costs of about $3 billion over the first 5 years for the disability provisions in H.R. 4170.)

This additional outgo from the DI fund—with or without reopening of past CDR cases under a medical improvement standard—probably would require earlier repayment of the interfund loans that were made to the Old-Age and Survivors Insurance Trust Fund from the DI fund in late 1982. Under the Social Security Amendments of 1983, these loans do not have to be repaid until 1989, and our estimates for present law indicate that the DI fund would probably not need earlier repayment. These loans might have to be repaid as early as 1985 to assure continued payment of DI benefits if H.R. 4170 is enacted. Even with repayment of the loans from the OASI trust fund in 1985, the DI trust fund ratio is estimated to decline to 11 percent—less than months' outgo—by January 1, 1989.

Also, the increased expenditures under the Ways and Means Committee's bill would reduce trust funds assets, increasing the likelihood that the automatic stabilizer provision in the law would be triggered. This would mean that the Social Security cost-of-living increases for December 1984 and possibly other years could be reduced—but only if wages increase at a lower rate than prices.

Now I want to comment on some of the major items of disability legislation that were considered in the first session of this Congress.

CONTINUATION OF BENEFIT PAYMENTS

The first issue I want to mention is the continuation of benefit payments during appeal. As I indicated earlier, the provision in the law expired on December 6. We directed the States to hold termination notices beginning December 7, because we needed time to revise the notices due to the expiration of continued payment and also needed to advise beneficiaries of their rights to a reconsideration hearing effective January 1.

We have notified the States to resume processing cessation cases, beginning this month. Of course, those States that are affected by court orders will process cases in accordance with the court orders. In the case of cessations effective for February, benefits will be payable for February and for 2 additional months—last check will be paid May 3 unless action is taken to reinstate continued payment.

MEDICAL IMPROVEMENT

The administration strongly opposes section 901 of H.R. 4170 which would establish a separate standard of disability for those already on the rolls. About three-quarters of the cost of the House bill is attributable to this provision alone.

There are no statements in the statute as two what standard to use in determining a disability beneficiary's continuing eligibility for benefits. We now use the same standard that we use in initial disability cases.

Both H.R. 4170 and the disability amendments introduced by Senators Cohen and Levin late in the first session of this Congress would provided a medical improvement standard for terminating disability benefits. As part of the disability reforms, we undertook a top-to-bottom review of disability policies and procedures, including the issue of whether an acceptable medical improvement standard could be developed. After months of study of the issue and consideration of the standards in both the Senate and House bills, we have concluded that we must strongly oppose a medical improvement standard.

A basic problem with a medical improvement standard is that it would create different standards of eligibility for initial claims and for continuing disability reviews. This would be unfair and inequitable to people now applying for benefits who could not receive benefits even though they are in the same condition as some people now on the rolls.

Also, those very ineligibles that the 1980 amendments sought to remove from the rolls would continue to get benefits if a medical improvement standard were adopted.

In addition to these serious concerns, we believe that reforms in the disability program now underway make such a standard unnecessary. The most important of these reforms are the face-to-face evidentiary hearing at reconsideration and our top-to-bottom review of the disability program.

Most importantly, we believe that most of the pressure for enactment of a medical improvement standard has come because of the initiation of CDR's as mandated by the Congress in the 1980 disability amendments. Beneficiaries had not expected to have their eligibility reviewed. Now, when a person is awarded disability benefits he is told that his continued eligibility will by reviewed and that SSA will periodicaly redetermine whether he remains so disabled as to be unable to work.

For all of these reasons we believe that a medical improvement standard is not in the best interest of the disability program, and we strongly oppose enactment of such a provision even if applied prospectively only.

FACE-TO-FACE INTERVIEW AT INITIAL LEVEL

Another proposal that has been suggested by some disability interest groups and is contained in H.R. 4170 is to eliminate the reconsideration step in the appeals process for disability cessation cases and, instead, provide a face-to-face interview at the initial level for disability cessation cases. The face-to-face interview would take place after a preliminary unfavorable decision was made but before a final decision was issued. The disability amendments introduced by Senators Cohen and Levin would not eliminate the reconsideration step but would instead require demonstration projects in 5 States on a face-to-face interview at the initial level.

We agree with the need for early fact-to-face contact between the disability beneficiary and a decisionmaker to assure correct continuing disability decisions. That is why we supported the face-to-face evidentiary hearing at reconsideration that was provided by Public Law 97-455. However, we oppose such pre-termination hearings because they would abandon the idea of a reconsideration hearing before it is fully tested. The new reconsideration process mandated by Public Law 97-455 should be given a fair trial, particularly in view of the highly successful pilot project results. We have strongly urged the Congress to give this approach a fair chance before considering making a wholesale change.

MORATORIUM ON MENTAL IMPAIRMENT REVIEWS

Under another proposal—which is contained in H.R. 4170 and the disability amendments introduced by Senators Cohen and Levin—there would be a temporary delay of periodic review for all mentally impaired individuals until the criteria for evaluating mental impairments in the Listing of Impairments have been revised. We believe this provision is unnecessary since under the Secretary's disability initiatives SSA has stopped reviews of about two-thirds of mental impairment cases—those most prone to decisional error—until revised standards are developed. Also, because we expanded the definition of permanent disability, the number of mental impairment cases selected for review has been further reduced.

More importantly, the workgroup, which has been reviewing the criteria for evaluating mental impairments since July 1983, will be submitting its recommendations, and we expect to be able to implement their recommendations in the near future. In view of this progress, a moratorium in mental impairment cases is unnecessary.

APA RULEMAKING

Another issue that has been the subject of proposed legislation is making the public notice and comment requirements of the Administrative Procedure Act applicable to SSA rulemaking. We oppose this proposal because it could raise serious questions as to whether an SSA policy is subject to the APA notice and comment requirements. The APA provides that only substantive—not interpretive—rulemaking is subject to the public notice and comment requirements. State agencies or ALJs might question whether they should follow an SSA policy that has not been published under the APA on the grounds that it establishes substantive rather than interpretive policy. Such a situation would add confusion to the disability process and would greatly impede our efforts to assure that uniform standards are used to make disability determinations. Another serious problem is that the provision could be interpreted broadly by the courts with the result that interpretive rulings which contain detail wholly inappropriate for regulations would have to be issued as regulations.

COMPLIANCE WITH COURT ORDERS

This proposal in H.R. 4170 would require us either to recommend appeal of circuit court decisions with which we disagree or to acquiesce in the decision and apply it within the jurisdiction of the circuit court.

We strongly oppose this provision. HHS has always complied with the terms of court orders as they relate to individuals or classes of individuals named in a particular suit. However, our policy of nonacquiescence is essential to ensure that the agency follows its statutory mandate to administer the Social Security program nationwide in a uniform and consistent manner. In a program of national scope, it would not be equitable to people to subject their claims to differing standards depending on where they reside.

There are several reasons why we do not recommend appeal of all circuit court decisions with which we disagree. for example, if the same issue has been decided by a number of courts and the weight of the decisions agrees with our interpretation, we may decide not to recommend appeal of the minority of cases which disagree with our interpretation. To appeal all such cases would be administratively expensive, would be an inefficient use of limited Federal legal resources, and would aggravate the already heavy burden of litigation in Federal courts. If, on the other hand, the weight of the court decisions on a given issue does not agree with our interpretation, we generally recommend appeal of one or more of the cases and may also pursue other remedies such as recommending remedial legislation.

There would be enormous practical problems with circuit-by-circuit acquiescence since we would need to keep track of applicants as they move through the decision-making process, determine which circuit law should apply, and separately handle claims by jurisdiction. Special problems could arise where there are conflicting decisions within a single circuit, or a claimant or beneficiary changes residence whole a decision on appeal is pending.

The proposal would take away our option to continue to litigate issues already addressed by the circuit courts, thus undermining our ability to defend the many suits brought against the agency each year. Further, requiring us to appeal adverse court decisions to the Supreme Court or else follow them also ignores the severe limitations we face in seeking Supreme Court review. The Supreme Court seldom grants review in cases involving a statutory issue of first impression decided adversely to the Government.

CONCLUSION

In conclusion, I would like to reemphasize that the administration strongly opposes enactment of disability legislation. As I have discussed in my statement, we believe that the administrative and legislative reforms already accomplished, and in progress including the face-to-face evidentiary hearing at the reconsideration level; the expansion of the definition of permanent disability; the suspension of review of certain mentally impaired beneficiaries; the improved initial CDR interviews; and our on-going review of disability policies and procedures make further legislative changes unnecessary. Therefore, the very high costs of the disability provisions in H.R. 4170—about $6 billion in the first 5 years—are unacceptable, especially at the present time when the safety margins of the OASDI trust funds are relatively small.

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